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The KBG Foundation is dedicated to providing support, assisting in research programs and advocating to raise awareness about the syndrome.

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**INTERNATIONAL**  
**KBG**  
**Syndrome**  
**AWARENESS**  
**DAY JUNE 19TH**

## Behavior in KBG Syndrome

# What behavior issues are there with KBG Syndrome?

The vast majority of KBG patients report challenges with cognitive delay and/or behavioral issues. Because KBG Syndrome is a spectrum disorder, the impairments range from nearly indiscernible to severe.

Adults with KBG, report early corrective and reaffirming therapies produced the most positive outcomes.

Regression has been noted in nearly 50% of the population.

## INCIDENCE IN KBG SYNDROME

Patient reporting in KBG Syndrome shows over 90% of patients have behavioral issues with or without memory involvement.

## PROGNOSIS

Early intervention is crucial to improved outcomes. Where KBG is present there should be no delay in beginning treatment.

## TREATMENT

As a spectrum disorder there is currently no comprehensive therapy. Corrective behavior therapies as well as medications have been used with success.



## Things to look for:

The most common symptoms in KBG Patients reporting behavioral issues include:

### EASILY DISTRACTED

Limited attention span as well as the need for additional sensory input creates focus issues in KBG patients.



### REPETITIVE BEHAVIORS

Patients report repetitive questions with no recognition of responses. KBG patients often require multiple responses before comprehending.

### MELTDOWNS

According to patient reports, meltdowns due to frustration, and lack of comprehension are common.



### DELAYING BEHAVIORS

Patients tend to take longer than expected to perform daily tasks (such as getting dressed and brushing teeth). The root cause is unknown.

### EMOTIONAL OUTBURSTS

Outbursts are extremely common and can last for hours. These reactions tend to be connected with fear and the inability to communicate/understand needs.



### LACK OF UNDERSTANDING CONSEQUENCES

Rarely do KBG Children comprehend consequences to their actions. Even into adulthood we find some confusion about reactions to actions.

## Therapies to try:

Unfortunately, there is no standard therapy or treatment for the behavioral issues seen in KBG Syndrome. We polled the family group about successful treatments they have used and listed them here for reference. As always, discuss your options with your medical provider.

### MEDICATIONS

While over 50% of KBG patients have chosen not to medicate for behavior, there are many who do with success. The most recent poll lists the top medications in order of rate of use:

Melatonin  
Ritalin  
Concerta  
Adderrall  
Prozac/Zoloft

### BEHAVIORAL THERAPIES

KBG Patients, not using medication, often rely on ABA (Applied Behavior Analysis) with success.

Parenting therapies also show good response with Triple P (Positive Parenting Program) a close second to ABA.

Cognitive Behavior Techniques have also been used with a positive outcome.

Gluten and casein-free diets have also shown positive response.

The key to most therapies with KBG is to start as soon as traits appear and stay as consistent and patient as possible. Do not delay seeking help, the earlier therapies are instituted, the better the outcome.

