



KBG SYNDROME FOUNDATION FUNDRAISING PACKET



Congratulations and welcome to the KBG Foundation FUNdraising effort! We appreciate your interest in raising funds to help KBG individuals and their families and hope this packet will help you get started!

Let's go!



ABOUT

The KBG Foundation



What do I tell someone when they ask about the Foundation?

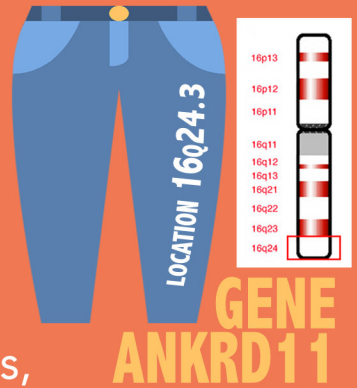
- ➔ Founded in 2015
- ➔ A 501(c) 3 US nonprofit
- ➔ Provides support to over 600 members and their families
- ➔ Funds research efforts
- ➔ Tax deductible Nonprofit
- ➔ All Volunteer board

Uncommon ANSWERS to COMMON questions:



WHAT is KBG Syndrome?

KBG Syndrome is a rare genetic disorder caused by a mutation on the ANKRD11 gene, associated with a spectrum of challenges, including developmental delays, cognitive disabilities, behavioral disorders, autism, seizures, hearing loss, skeletal anomalies, heart complications and gastrointestinal problems. Most people with KBG share at least some physical traits, including a triangular face, heavy eyebrows, curved fingers and spine, and short stature.



How **many** people have KBG?

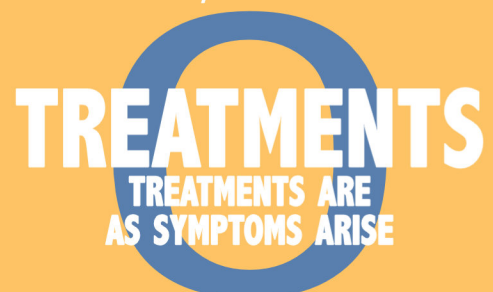
Patient reporting tells us that there are currently over 600 people worldwide diagnosed with KBG. In 2015, before the Foundation, there were only 60 identified cases. This illustrates the importance of our patient efforts.

Is there a **cure**?

There is no cure and no comprehensive treatment for KBG Syndrome. It's a 'treat as you go' syndrome with a good prognosis. However, KBG can and does have a profound impact on quality of life.

What, most likely, can cure KBG?

Advancements in gene therapies!



Fundraising ideas

Sometimes the easiest ideas are the most successful. Don't discount the old standards, people are comfortable and know what to expect.

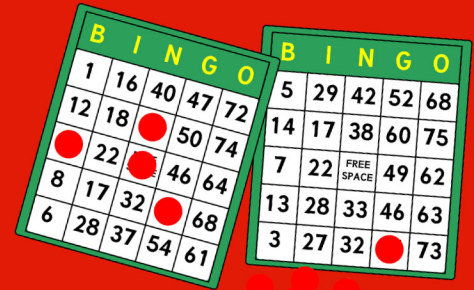
Hold a yard sale!

Bingo the night away!

Have a bake sale!

Partner with a local eatery!

Create a letter-writing/email campaign!



Host a Golf Tournament!

Hold a social media fundraiser!

Enjoy an ice cream social!

Do a Walkathon or 5K!

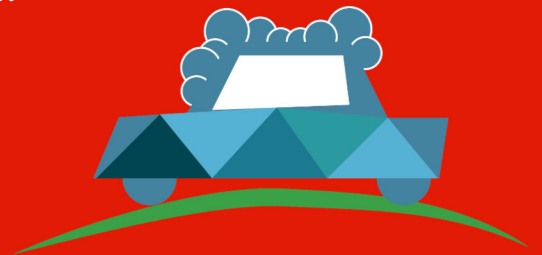
Organize a sponsored night out!

Car wash!

Babysit for a parents night out!

Food truck event!

Hold a paint night with your friends!



Don't hesitate to tell your story, people willing to give always want to know why they are giving and your story is the most important reason. Answer the question:

Why is **KBG Syndrome** so important to you?

There are many ways that your story can impact others, it's not just about making money, it's about raising awareness and increasing acceptance. Some ways your story has impact:



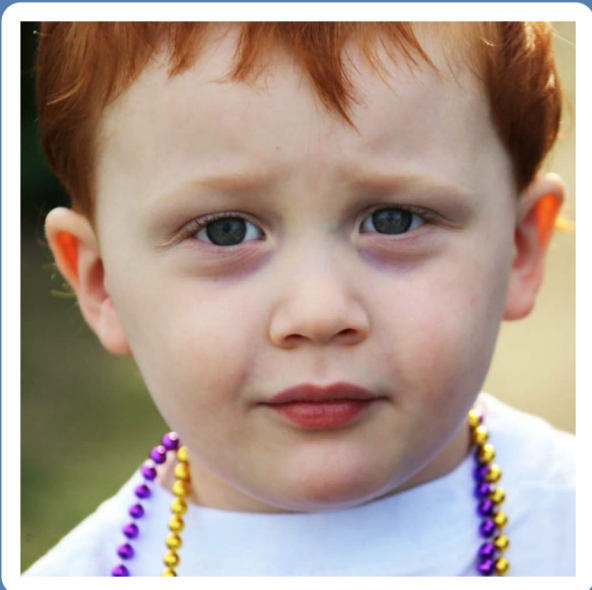
Sharing your story on **social media**, and in local newspapers, raises awareness and lets others with KBG know they are not alone.

Creating a **letter writing campaign**, with your story at the center, lets others know why they should donate. Having a specific personal goal lets them know how their donation will be used.

It helps **YOU** be comfortable and accepting of the KBG Diagnosis!

Tell your story

Your words have power



Letter writing campaigns are designed to be hand written or typed letters requesting monetary Donations, in-kind donations, auction items, sponsorships, matching corporate donations, volunteer time and more.

Letters should be specific about the goal of your campaign (what you hope to achieve) and personal enough to create a meaningful bond between you and the recipient.

Letter writing campaigns can be used year-round and are a great awareness tool!

If you need help writing your letter, contact fund@kbgfoundation.com and we'll send you some samples!

USING Social Media



This is when your story will make the biggest impact. Start your campaign by sharing your story and explaining why KBG Syndrome is important to you.

The Foundation has statistics you can use to help people understand: KBG is a systemic syndrome that affects the entire body in a variety of ways. Finding a treatment is not only extremely difficult but also very costly since research is limited.

The most important part of a social media campaign is the personal touch. You can achieve that by not just telling your story but using images with your posts. Posts with images not only get more attention but they also get more shares, increasing your reach. Sharing every day or every other day reminds people about your effort.

Use hashtags and tags such as: **#KBGSyndrome** **#KBGFDN** **#everylinkmatters** and **@KBGFdn** and when someone donates to your fundraisers be sure to tag them in a thank you post.

#everylinkmatters

Include
CAPTIVATING
Pictures



Keep it close.

While it's sometimes very difficult to ask for help, it's better to start by asking the people that you know well.

Friends and family,
Co-workers,
Neighbors,
Local Businesses

Be respectful, keep it simple and sincere



Every

Link

Matters

THINGS you need to know

Once you have decided what type of fundraiser you want to hold, The Foundation has resources that can help. Such as:

1. The Event **PLANNING** Kit

This kit includes documents like:

Event Proposal - Requests Foundation Assistance.

Event Checklist - Guidelines for when, and what to do leading up to and during the event/fundraiser.

Volunteer Application - Anyone wanting to volunteer should fill out a form like this.

Sponsorship Levels - It's not only about helping raise Awareness for KBG, sponsors get other perks

2. The **Style** GUIDE

Use this Guide to make sure the colors, graphics and wording you use are in line with approved Foundation materials.



Important email

ADDRESSES



Fundraising questions and help: : fund@kbgfoundation.com

Press release and media help: : pr@kbgfoundation.com

Marketing material requests: info@kbgfoundation.com

For general information: contact@kbgfoundation.com