



# Seed Funding Program 2022—2023

# KBG Foundation Seed Funds

The KBG Foundation is a 501(c)(3) nonprofit organization dedicated to providing support for patients, assisting in research programs and raising awareness about KBG Syndrome. We welcome and are actively seeking to connect with researchers who are currently or are interested in studying KBG Syndrome, mutations in the ANKRD11 gene, the genesis of the mutation and any potential treatments.

Our **Seed Fund Grant Program** is intended to expedite research projects by supporting investigative research into KBG Syndrome and ANKRD11 or otherwise enabling projects exploring KBG Syndrome and potential treatments to move forward.

For the fiscal years 2022 and 2023, the Foundation will award up to three grants of up to \$10,000 each year. Application is open to certified researchers with demonstrated interest in and capability to advance the understanding and treatment of KBG Syndrome.

Awards will be issued with 50% of the funds up front with the remainder issued after six months or the completion of the project, whichever comes first.

## About the Seed Funds

The Foundation will fund up to **three \$10,000 one-time** grants each year.

A screening committee will review applications as they are received and make recommendations to the KBG Foundation Board of Directors. Applicants will be notified of the outcome of their application. Those awarded Seed Funds will be sent a letter of acceptance contingent upon the Seed Fund Program Agreement (see below).

## Working with the KBG Foundation

The KBG Foundation has a patient registry scheduled to launch in the fourth quarter of 2022. Researchers are welcome to and encouraged to request data from this pool through the Foundation. The Foundation will give preference to researchers using our registry.

In addition, the Foundation maintains a closed patient group on Facebook. Researchers may contact the Foundation to learn about connecting with patients in this group or about using existing data the Foundation has gathered.



# Application Process

Applications are to be submitted in the form of a one-page request that includes the following:

1. **Applicant name**
2. **Institution**
3. **CV or bio sketch**
4. **Phone and email**
5. **Describe in lay terms (up to one page) the work for which you are seeking funds.**
6. **Is this for investigative research or otherwise needed to prepare for pursuing grants for a larger research project? If so, please explain.**
7. **What is your hypothesis and what are the measurable outcomes?**
8. **What is your timeline/anticipated duration of your project?**
9. **State whether you are seeking the full \$10,000 available this funding cycle.**(Please note: The Foundation will fund personnel salaries; consumables, reagents, contract services, and technical services. We do not fund investigator salary or travel expenses to conferences and meetings, institutional overhead, or publication costs.)
10. **Indicate** any special time constraints or other circumstances you believe are important to our decision-making.

**Applications for the 2023 round are due April 30, 2023.** Applications may be emailed to [research@kbfoundation.com](mailto:research@kbfoundation.com) or mailed to KBG Foundation, Seed Fund Program, P.O. Box 251 Manchester, MD 21102.

The KBG Foundation Board of Directors will respond to your request with an approval, denial or further questions as quickly as possible. The application will be reviewed by a committee of Board members and a scientific oversight member prior to full Board and subject to Scientific Advisory Board review.

# Funding Agreement

If the Foundation awards Seed Funds, the researchers must agree to the following:

- The first \$5,000 will be sent based on the date work is expected to begin.
- The remaining \$5,000 will be sent after six months or the completion of the project, whichever comes first. To obtain the remainder, the researcher will send a written request for the balance of the grant with a short update of the work.
- The researcher agrees to thank the KBG Foundation for its assistance in any publications and public-facing media related to the work. Any information used in his or her study

obtained through the KBG Foundation Patient Registry or existing Foundation research should be cited as such.

- The KBG Foundation wants to promote the work being done to advance understanding of and find treatments for KBG Syndrome as well as provide transparency on how the Foundation's funds are spent. The Foundation will announce the awarding of Seed Funds in as timely a manner as possible through our media channels. The Foundation will work with the researcher regarding the announcement.

## Stay Connected

Thank you for your interest in furthering the understanding of KBG syndrome, how it impacts the patient and their caregivers and in raising awareness for rare diseases.

We encourage you to remain engaged with the KBG Foundation:

The KBG Foundation on Facebook is a conduit between the clinical and research communities and the closed family group(s):

Main page: [facebook.com/KBGFdn](https://facebook.com/KBGFdn)

Professionals Group: [facebook.com/groups/KBGProfessionals](https://facebook.com/groups/KBGProfessionals)

Private Family Group: [facebook.com/groups/kbgsyndromefamilygroup](https://facebook.com/groups/kbgsyndromefamilygroup)

Follow us on LinkedIn: [linkedin.com/company/kbgfdn](https://linkedin.com/company/kbgfdn)

We look forward to combined exchange of information and ideas because...