



## FKC Clinic Staff FAQs

### What is the My Reason research program?

My Reason is a new program that is asking for people of all backgrounds to participate in a registry study that supports kidney disease research. By creating the My Reason health database, researchers can study how to better help kidney disease patients.

Participants can help this research by consenting to share their DNA and health history. This advances the ability to develop new drugs for kidney diseases.

### What is a registry study?

Registries are data collection tools typically used to better understand long-term trends in a specific population, such as patients with a particular disease or exposure to a certain treatment. However, if designed appropriately, registries can be used as a data source within which clinical trials can be performed.

### Who is eligible?

#### Included:

- People with and without kidney disease
- Adults 18+ (19+ in Alabama, 21+ in Puerto Rico)
- U.S. residents (including Puerto Rico)
- FKC and non-FKC patients

#### Excluded:

- People in jail
- People who cannot give consent due to physical, mental, and/or permanent medical limitations

### How should I approach a potential patient for the program?

1. Provide a copy of the My Reason brochure in English or Spanish and let the patient know they have an opportunity to participate in a research study
2. Answer basic questions that are included in this FAQ
3. For additional questions, direct them to 855-4MY-RESN or [MyReason@frenova.com](mailto:MyReason@frenova.com)
4. For consent, direct them to [WhatsYourReason.com](https://www.whatsyourreason.com); patients may use a clinic tablet for review and consenting
  - FKC patients only need to provide consent to participate; previous blood samples will be used

### What can I tell an FKC patient who might be interested in participating about what will happen?

- We need permission to use a leftover blood sample at Spectra Laboratories, Inc.; we do not need additional blood draws
- We need permission to access participant medical records
- The information from this program will help researchers learn more about the genetics that contribute to kidney disease to help improve treatments
- For consent, direct them to [WhatsYourReason.com](https://www.whatsyourreason.com)



**For other questions patients may have:**

*Do I need to have kidney disease?*

No, the program is open to people with kidney disease and those with no history of kidney disease.

*What happens if I say yes?*

Participants will give a blood sample, as well as permission to access their medical records. If they are an FKC patient, they do not need to give another blood sample, only consent. That's it.

*Will data be private?*

Protecting privacy is critically important to the My Reason study team. Appropriate safeguards are in place to keep participant data safe.

*Why should I participate?*

Everyone's DNA and medical history are unique. It is this uniqueness that makes each participant's contribution important. The more people who participate, the better the data, the better it will be for a future kidney patient.

*How will my information be used?*

The information we receive from your samples and medical records will be included in a database that will be used by kidney disease researchers.

*What is the end goal?*

To create a set of data that doctors and researchers can use to improve medical treatments for kidney disease.

*How do I get involved?*

To learn more, visit [WhatsYourReason.com](http://WhatsYourReason.com).