

# GUIDE TO WORKING WITH A GENETIC COUNSELOR



## How can I get genetic testing and what is the process?

### Follow these 5 steps:

#### Step 1

#### Ask for a Referral

It can be uncomfortable asking your doctor for a specific test. It's important to remember that as a patient, you have the right to request specific care and information about your health.

Before you ask, you may want to prepare your reasons for wanting genetic testing. Some reasons to consider include:

- A family history of kidney disease
- The cause of your kidney disease has not been diagnosed
- You are thinking of starting a family and want to know if your child could inherit kidney disease

When you ask your doctor, you can say:

*"I am interested in having genetic testing done because \*reason\*, can you refer me to a genetic counselor?"*

If your doctor does not refer you, make sure they document that they have refused your request.

Another way to seek out genetic counseling is to search for a genetic counselor in your area using the [National Society of Genetic Counselors](#) search tool. You can also call your health insurance company to ask for a list of genetic counselors covered by your plan.

#### What is genetic testing?

Genetic testing looks for changes in your DNA that can cause kidney disease. It is less invasive than other kinds of testing and can help determine a diagnosis and create a personalized treatment plan. Genetic testing can also help you understand the risk of kidney disease for your family members.

#### What is a genetic counselor?

A genetic counselor is a healthcare professional that has been trained in medical genetics (using genetic information to understand health) and counseling. They can guide and support you if you are interested in genetic testing and they are able to interpret any genetic test results.

Genetic counselors will never make any decisions for you. They give you resources and information, but the decision to move forward with testing and any actions after receiving results are always up to you.

## Step 2

### Preparing for your appointment

#### To prepare for your first meeting:

- Gather health information (*like recent test results or your family's health history*)
- Ask someone to come with you (*to help you take notes*)
- Call your insurance company (*find out if they will cover the cost of the test and/or meeting with a counselor*)
- Prepare your questions (*type out a list on your phone for easy reference*)

#### Questions to ask during your appointment

- How accurate is the genetic test?
- What are the possible results?
- What are the advantages/disadvantages of genetic testing, or a certain test?
- How long will it take to receive my test results?
- Should my family get genetic testing?
- Is this test covered by my insurance? If not, is financial assistance available?

## Step 3

### During your appointment

Genetic counseling appointments vary in length, but they usually last between 45 and 90 minutes.

You can meet with a genetic counselor before you have testing done, or you can meet with them after your test results come in.

#### During the appointment, your genetic counselor will:

- Go over your health history and your family's health history
- Perform a physical exam and recommend other tests if needed
- Go over the reason for your visit
- Go through testing options and help you decide what is best for you and your family based on your needs and values
- Answer any questions you may have

#### If you decide to move forward with testing, your genetic counselor will:

- Help determine what kind of genetic test is best for you
- Arrange testing (which is often completed as part of a genetic consultation)

## Step 4

### Genetic Testing

Once you have decided on a genetic test and it has been ordered by your genetic counselor, a sample will need to be collected. This could include:

- Blood
- Saliva (*spit*)
- Amniotic Fluid (*the fluid surrounding your baby during pregnancy*)

Your sample will be sent to the facility where the testing is done.

## Step 5

### Review of results

It usually takes a few weeks for your results to arrive, but this can vary depending on what kind of genetic test you had and the facility that is doing the testing.

#### Once your results are in, your genetic counselor will:

- Let you know your results are in, you may need to schedule another appointment to go over the results
- Discuss what your results mean
- Go over steps for preventing disease, managing disease, and any other next steps that are appropriate for your results
- Provide you with emotional support and other resources

Your genetic results may be shared with your primary care provider and added to your medical records.

Note: Schedule a follow-up appointment with the provider who ordered your test to review your results if you didn't go through a genetic counselor.

To learn more visit:  
[KidneyFund.org/Genetic-Testing](https://KidneyFund.org/Genetic-Testing)



American Kidney Fund's **Answers Unlocked** educational campaign is supported by:

