

GUIDE TO TALKING TO A GENETIC COUNSELOR



Genetic counselors are health professionals trained to help people understand genetic testing. If you have kidney disease, genetic testing may help you get answers about the cause of your kidney disease and get the right treatment. This guide will help you locate a genetic counselor and prepare for your appointment.

Finding a Genetic Counselor

Genetic counselors work in many different settings, including:

- Hospitals
- Clinics
- Research Centers
- Private practices

Some genetic counselors may also use telehealth, meaning you can meet with them virtually for your appointments.

To find a genetic counselor, you can:

- Talk to your primary care provider or kidney doctor for a referral to a genetic counselor.
- Use findageneticcounselor.nsgc.org, a website from the National Society of Genetic Counselors. You can filter by appointment type and specialty, including nephrology.
- Call your insurance company for a list of genetic counselors that they cover.

Meeting a Genetic Counselor

You will likely meet with your genetic counselor one or two times. Your first appointment will be a consultation to decide if testing is right for you, and your second appointment will review the results of your tests.

Questions to ask your Genetic Counselor

BEFORE YOUR FIRST APPOINTMENT

To prepare for your first appointment, gather the following information:

- Your reasons for seeking genetic counseling services
- Your health history
- Your family health history

Before your first appointment, you can ask:

- What documents should I bring with me?
- Do I need to fill out any questionnaires or paperwork?
- Will my insurance cover genetic testing?

DURING YOUR FIRST APPOINTMENT

During your first appointment, your genetic counselor will review your health information, your family history and different testing options. If you decide to move forward with genetic testing, they will take a sample of your saliva (spit) or blood. This will be sent to a lab, and in a few weeks, your genetic counselor will receive the results.

During your first appointment, you can ask:

- What are the pros and cons of each type of test?
- What are the different types of results I could receive?
- What is the testing process and how long does it take to get results?
- Will I need to repeat this test in the future?
- How will you contact me to discuss the results?

Your results:

When your results come in, your counselor will review them with you. They will help you understand what your results mean, whether your family members should be tested, and answer your questions.

When you review your results, you can ask:

- What do these results mean for my cause of kidney disease?
- What do these results mean for my family and their risk of developing chronic kidney disease (CKD)?
- Are there any support resources available to me?

Note: Not every genetic counselor will make a second appointment; they may discuss this through a video or phone call instead. Talk to your genetic counselor to see what option is best for you.

Depending on your results, you may meet with a genetic counselor for a third time. These appointments might review disease management, education about the results, how to discuss your results with family members, and information on additional testing.

Some things to keep in mind for all appointments:

- Bring your medical history and any test results with you
- Write down your family's health history. Include their gender, their relation to you, if they had kidney disease, and how old they were and what caused their death (if applicable)
- Write down your questions ahead of time so you can refer to them during the appointment
- Ask someone to come with you for support, they can take notes and ask any questions you might forget

To learn more visit: KidneyFund.org/Genetic-Testing



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