American Kidney Fund®
FIGHTING ON ALL FRONTS

APOL1-mediated kidney disease: Connect with a genetic counselor

Every person has two copies of the APOL1 (apolipoprotein L1) gene.

However, mutations (changes or variants) in one or both APOL1 gene copies can raise the chance of kidney disease in people of Western and Central African descent (which may include people who identify as Black, African American, Afro-Caribbean, or Latina or Latino). Doctors may refer to this as APOL1-mediated kidney disease (AMKD).

If you are thinking about genetic testing or have learned that your or a family member have mutations in the APOL1 gene that increases risk for kidney disease, a genetic counselor can be a great resource.

Learn more about genetic testing for APOL1 gene mutations that cause AMKD.

Genes (and mutations or variants in genes) are passed down from parents to children. You have two copies of each gene: one from each of your parents. Some individuals have a mutation in one or both copies of the APOL1 genes.

Benefits of genetic testing

Genetic testing looks for mutations (changes or variants) in your DNA. Genetic testing is the only way to see if you have a APOL1 genetic variant in one or both copies of the gene.

Your results will:

- Help you understand the cause of your kidney disease
- Help you and your health care team be informed about disease progression, make a plan to help you manage your health, and to identify possible clinical trials to explore other treatment options
- Help you to have conversations with your family about possible health risks

Genetic testing is a medical test.
Results may be added to your health records, just like a blood test would.

Getting the right counseling and education

If you decide to get genetic testing, experts recommend it should be with a genetic counselor. A **genetic counselor** is a health care professional with special training in genetics and counseling. This counselor can help you:

- Decide if a genetic test might be right for you
- Understand your genetic test results and treatment options
- Cope with emotions during the testing process
- Get a referral to other doctors, support and advocacy groups or clinical trials
- Understand if your family is affected and how to best talk with them about their chances of kidney disease

You may meet a genetic counselor in-person in a health care setting or through a telehealth appointment.

How to find a genetic counselor

After you get your testing results, it's important to make an appointment with a genetic counselor to review them together. You can also meet with a genetic counselor **before testing** to help with your decision about getting tested.

The best way to find a genetic counselor is to ask your doctor for a referral. Some healthcare practices and genetic testing laboratories offer genetic counseling services.

If your doctor cannot give you a referral, you can:

Search for a clinic near you through the American College of Medical Genetics and Genomics:

clinics.acmg.net

Find a genetic counselor through the National Society of Genetic Counselors:

findageneticcounselor.nsgc.org

Contact your insurance company to find genetic counselors covered under your plan.

Prepare ahead of time

Gather information your counselor may ask for, including:

- Your medical history
- Information on genetic conditions or other significant health concerns diagnosed in your family
- A copy of a relative's genetic testing results (if available)

Think about the questions you may want to ask, such as:

- **What kind of information can genetic testing give me?**
- **How can genetic testing help me to know more about a genetic risk?**
- **What are the pros and cons of getting genetic testing done?**
- **If my family member has APOL1 gene mutations, what are my chances of also having them?**
- **If I have APOL1 gene mutations, are my family members at risk?**
- **Can I pass this gene mutation on to my children?**
- **What are my next steps if I have APOL1 genetic mutations?**
- **Will my test results and an explanation be put into my electronic health records?**

Can the results of my genetic tests be used against me?

There are laws to protect you against genetic discrimination. Genetic discrimination is when an employer or insurance company treats you differently because you have a genetic mutation that causes or raises your chance of a disease.

The federal Genetic Information Nondiscrimination Act (GINA) makes it illegal for employers and health insurance carriers to discriminate based on genetic test results:

- Health insurance carriers cannot deny you coverage or charge you more
- Employers cannot use results to make decisions about hiring or promoting you

GINA does not protect your ability to obtain life, disability, or long-term care insurance. If your employer has less than 15 employees, they are exempt from the protections provided by GINA as well. If you receive insurance through the federal government or the military, GINA does not apply to you. Some states have additional laws that provide more protection, you can check to see if this is true in your state.

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Does health insurance cover the cost of genetic testing and counseling?

Many health insurance plans cover (pay for) the cost of genetic testing when your doctor recommends it. The cost can range from less than $100 to more than $2,000, depending on the type of test.

Before you have genetic testing, call your insurance company to ask about costs, such as:

- **Does my plan cover genetic testing and counseling?**
    - If yes, what services are covered? What services are not covered?
- **Do I need a referral to see a specialist?** A referral is permission from your primary care doctor or insurance plan to visit another doctor.
- **Do I need prior authorization before getting a genetic test?** Prior authorization is permission from your insurance company before you get certain health care services, such as treatments or medical equipment. If you do not get permission before the services, your insurance may not cover costs. It is also called preauthorization or prior approval.
- **What are the costs for my plan**, such as my:
    - **Deductible?** This is the amount you pay before insurance starts paying the costs.
    - **Copay?** This is the amount you pay each time you get a health care service, such as a doctor's visit or filling a prescription.
    - **Out-of-pocket maximum?** This is the most you will pay for covered services for the year. After you pay this amount, your insurance company will pay all of the costs of covered services.

A genetic counselor or social worker can also talk with you about costs and insurance. They may also know of programs that cover the cost of genetic testing if your insurance will not pay for it or you do not have insurance, such as by joining a clinical trial.

You can also get genetic testing directly from a testing company, such as:

arkanalabs.com/services/apol1

natera.com/renasight

labcorpapol1test.com

These companies accept insurance, some may offer no cost APOL1 testing for eligible participants or you can pay for the test yourself. They also offer genetic counseling before and after the test.

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