

# What is APOL1-mediated kidney disease (AMKD)?



## APOL1 gene mutations

Genes are in the part of your cells that contain DNA. You have two copies of each gene: one from each of your parents. Genes are passed down (inherited) from parents to children, including genes that have mutations (a change or variation).

The APOL1 gene makes a protein in your immune system, which is your body's cells and tissues that fight infection. Everyone has two APOL1 genes. Typically, the APOL1 genes make a helpful immune system protein. But some people are born with mutations in one or both APOL1 genes.

## What is the connection to the kidneys?

If you inherited an APOL1 mutation in your genes, it can:

- Cause damage to parts of your kidneys that filter blood
- Sometimes cause cells in your kidneys to die, which leads to damage and scarring in the kidneys and can lead to kidney failure

## How does this affect my chances of getting kidney disease?

If you have two of the APOL1 gene mutations, you have a higher chance of getting kidney disease and even kidney failure. It is estimated that one in five people with two copies of APOL1 mutations get kidney disease.



## Who is more likely to have APOL1 gene mutations?

You are more likely to have APOL1 gene mutations if you are from Western or Central Africa or have an ancestor who came from these regions. This includes people who identify as:

- Black
- African American
- Afro-Caribbean
- Latina/Latino

## AMKD gets worse over time

AMKD is progressive, which means it gets worse over time. Medicines for kidney disease do not treat the genetic cause of AMKD and often do not stop progression to kidney failure.

Although medicine does not treat the genetic cause, it is important to take it as your doctor tells you to. If you have AMKD, your kidney disease may get worse faster than other types of kidney disease. Over time, you may need dialysis or a kidney transplant.



## How can I monitor my kidney health?



Find a kidney doctor (nephrologist) if you do not already have one.



Measure your blood pressure each month and write it down to bring to your doctor's appointments. You can use a home blood pressure cuff.



Visit your doctor once a year so they can check your kidney function with a urine (pee) and blood test.

# How can I stay healthy if I have the APOL1 gene mutation or AMKD?

- Follow a healthy eating plan. This may include lowering the amount of salt (sodium) you eat.
- Take all of your prescription medicines the way your doctor tells you to.
- Be active for at least 30 minutes a day on most days of the week.
- Quit smoking or using tobacco.

If you have AMKD, getting kidney disease was not your fault. You may have been more likely to get kidney disease due to your genes.



**If you have an APOL1 gene mutation**, let your close family members (parents, siblings, children) know that they could have a higher chance of APOL1-mediated kidney disease as well.



**If you have the APOL1 gene**, consider taking part in a clinical trial. This could provide an opportunity for researchers to develop and test safe treatments for AMKD.

## Where can I learn more?

Use your smartphone to scan these QR codes:



Learn more about APOL1



Learn more about genetic testing and counseling

If you have questions about APOL1-mediated kidney disease, be sure to talk with your doctor.