

PROVIDER GUIDE

Communicating APOL1 genetic risk to patients participating in the GUARDD research study

Q: What are genes?

A: Genes are threadlike particles made of DNA found in all the cells in our bodies that carry instructions for how we look and how our bodies function.

Genes come in pairs. If there's a change in a gene, then we may not get the right instructions and this may cause health problems.

Q: What is the APOL1 Kidney Gene test I took?

A: Every human being has the APOL1 gene. In Africa, some people developed variations or changes in this gene to protect themselves from sleeping sickness. However, if you have high blood pressure, these variations also increase your chance to have kidney problems and have them at a younger age. You took a genetic test to see if you have variations in the APOL1 gene.

Q: What does my result mean?

A: APOL1 Positive (Increased Risk). You have two copies of the APOL1 variations, which increases your risk for kidney problems and kidney disease. You don't have kidney problems now and this does not mean you will definitely have kidney problems in the future. It does mean we need to make sure your blood pressure is under control and check your kidneys regularly through blood and urine tests to see how you are doing.

A: APOL1 Negative (Normal Risk). You do not have two copies of the APOL1 variations that increase risk for kidney disease. However, high blood pressure can still hurt or damage your kidneys, so we need to keep your blood pressure under control to lower this risk.

Q: Should I consider changing any medications I am taking?

A: No, there is no need to change your medications as long as your blood pressure is and remains under control. If your blood pressure is not under control now or in the future, your blood pressure medication may need to be changed to control your blood pressure better.

Q: Are my family members at risk? Can they get tested?

A: The APOL1 gene variation is passed from parents to children. There is a chance your family members may have the variation. At this time, the GUARDD study is only able to offer the test to adults between the ages of 18 and 65 who have high blood pressure and who get care where you get care. The GUARDD study doesn't offer the test to children, or to people who also have diabetes, as they don't have the high risk for kidney problems. If your family member is not a patient here, they cannot offer the test to them right now.

**For additional information you may contact the GUARDD Study Genetic Counselor,
XXX at (XXX) XXX-XXXX**