



GUARDD

Genetic testing to Understand and
Address Renal Disease Disparities

Thank you for taking part in the GUARDD study. We aim to learn whether getting the APOL1 genetic test is helpful to patients and their doctors. This test tells us if someone with high blood pressure also has a higher risk of getting kidney disease.

This booklet has information about high blood pressure, kidney disease and the APOL1 genetic test. It also has suggestions on how you can talk to your doctor about the test and what the results mean for you. You can share this booklet with your family or friends so they can learn with you.

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Blood Pressure

Blood pressure is important to your health. As you may already know, if left uncontrolled, it can lead to a stroke or heart attack. Many people do not know that it can also lead to problems with your kidneys.

How can my blood pressure affect my kidneys?

Your kidneys filter blood through blood vessels and high blood pressure can weaken or damage these vessels. This can make it harder for kidneys to work well. If your blood pressure is high, you can have problems with your kidneys. When blood pressure is controlled, your risk of kidney disease is lower.

What can I do to control my blood pressure and help protect my kidneys?

Your doctor can help you manage your blood pressure through exercise, diet and medication to help prevent kidney disease. Make sure to check your blood pressure regularly. Your blood pressure is a goal that is decided between you and your doctor. However, your blood pressure should generally not be over 140/90.

Your doctor can check for early kidney disease by testing for protein in your urine. Too much protein in your urine could be a sign of kidney damage. There is also a blood test called a “creatinine test” that your doctor can do to check for kidney problems.

Kidney Health

Kidneys

The kidneys are organs in our bodies that help remove waste and excess fluid from our bodies through urine. They also help balance our body's chemicals. We all have 2 kidneys. Each is about the size of a fist.

What is Chronic Kidney Disease (CKD)?

Chronic kidney disease, or CKD, affects about 26 million American adults. Over time, people with CKD can lose their kidney function, which can make them very sick. Some people will need lifelong dialysis or a kidney transplant. CKD happens slowly over a long period of time. People usually have no pain or symptoms from CKD until it is advanced. The only way you can tell if you have early CKD is to check if there is too much protein in your urine or creatinine in your blood. Finding CKD at an early stage will not cure it, but you and your doctor can keep it from getting worse.



No CKD

Great! - Kidneys are working fine. Controlling blood pressure helps people stay here.



Stage 1 and Stage 2 CKD

Be careful - Pay very close attention to kidney health. Work with your doctor to take precautions.



Stage 3 CKD

Serious - Treatment may soon require dialysis or transplant. Talk to your doctor and possibly a kidney specialist.



End Stage Renal Disease

Critical - Treatment may require dialysis or transplant.

Genes and Genetic Testing

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.

If there's a change in a gene, then our bodies may not get the right instructions and this may cause health problems. Children inherit half of their genes from their mother and half of their genes from their father. That's why most of us look like our parents and why some illnesses are passed from parents to children.

The APOL1 Gene

Everyone has the APOL1 (Apolipoprotein L1) gene. People who have inherited variations or changes in this gene from their parents have a greater risk for getting CKD. The risk is higher for people who have high blood pressure but who do not have diabetes. It is also much more common in people of African ancestry and very rare in people of European ancestry.

How do I know if I have variations in my APOL1 gene?

A special blood test can show if we have mutations or variations in this gene.

Why do more people of African Ancestry have the APOL1 gene change?

Many, many years ago, a group of people in Africa developed variations in APOL1. These variations helped them survive sleeping sickness which was spread by insects in their area. Scientists have recently learned that these same variations also increase people's risk for getting CKD.

Now What?

I have received my genetic test result. What should I do?

Talk to your doctor

- You may share the letter with the result of your genetic test with your doctor. Discuss what your APOL1 test result means for you specifically. Your doctor knows you best.

Control your blood pressure

- Usually people manage blood pressure through their medication, diet and exercise.

Monitor your blood pressure and kidneys

- Make sure your blood pressure is checked every 3-6 months. Visit your doctor at least yearly for blood and urine tests to check your kidney function.

Questions to ask your doctor:

- What is my blood pressure? Is it OK?
- Should I be tested to check my kidney function?
- Should I consider changing any medications I am taking?
- What can I do to prevent CKD?

Keep in mind that information about variations in the APOL1 gene is very new so your health care providers may be learning about it too! It is important to work closely with your provider to make a plan to help manage your health.

Blood Pressure Log

Please use this to keep track of your blood pressure readings. Most people's blood pressure should not be over 140/90. You can use the "Comments" column to write about how you are feeling, or reasons your blood pressure may be high, such as missing a dose of your medication.

Date	Blood Pressure	Comments
Example: 02/02/2014	Example: 135/82	

More Resources

Here is a list of useful websites with more information about kidney health, blood pressure and genetic testing.

Kidney Disease and Kidney Health

- **The National Kidney Foundation:**

<http://www.kidney.org>

- **Chronic Kidney Disease Fact sheet:**

<http://www.cdc.gov/diabetes/pubs/pdf/factsheets/kidney.htm>

- **National Kidney Disease Education Program:**

<http://nkdep.nih.gov/learn/keep-kidneys-healthy.shtml>

Toll free at 1-866-4 KIDNEY (1-866-454-3639)

High Blood Pressure

- **National High Blood Pressure Education Program:**

<http://www.nhlbi.nih.gov/about/nhbpep>

Call: 1-301-592-8573

Genes and Genetic Testing

- **Frequently Asked Questions about Genetic Testing:**

<http://www.genome.gov/19516567>

- **Video: What are Genes?**

www.guardd.org

Glossary

This is a list of useful words and phrases, along with their definitions:

- **CKD:** Chronic kidney disease. This is the gradual loss of the ability of your kidneys to do their job to filter out waste from the blood, through urine.
- **Creatinine Test:** This test measures the amount of creatinine in your blood. This test can see if your kidneys are working well or not.
- **Genes:** Genes are the material that our bodies use to determine the features or characteristics of your body. We get our genes from our parents.
- **DNA:** DNA is the material that your genes are made up of.
- **APOL1** - APOL1 (Apolipoprotein L1) is a specific gene that everyone has. If you are born with a variation in this gene and you have high blood pressure, it can increase the chance that you develop CKD.

If you have any questions, please feel free to contact the
GUARDD Study team at 212-659-9571 or
guardd@mountsinai.org.

You may also visit our website: www.guardd.org