

# Community Conversations: We Need to Learn from You!



Thank you for agreeing to take part in this Community Conversation. We need your ideas about the best way to care for kidneys. Please read this handout before coming to the meeting. We will answer all questions at the meeting.

## Kidney Disease in African Americans and Blacks

Kidney disease is a very serious problem in the United States. African Americans and Blacks have a higher chance of getting kidney disease than whites. Kidney disease starts with small changes that do not cause symptoms or problems, but affect how the kidneys work. These changes are called chronic kidney disease, or CKD.

CKD may get worse and lead to kidney failure. This is called “end-stage renal disease” (ESRD). For every white American with ESRD, there are 2 or 3 black Americans with ESRD.



## Risk Factors for Kidney Disease

Many things can put people at risk for CKD:

- Diabetes (sugar in the blood)
- High blood pressure or hypertension
- Being overweight or obese
- Smoking
- A family history of CKD
- Some medicines

African Americans and Blacks tend to have more diabetes or sugar in the blood and high blood pressure than whites. They may also have sugar in the blood and high blood pressure that is harder to control than in other groups. African Americans/blacks tend also to have less access to health care and may have lower quality of care. These problems may be due to problems with transportation, no healthcare providers or specialists in their area, or Medicaid/health care policies. Institutional racism may also contribute to these problems.

## Genetic Causes

Genes connected to CKD have been found. Genes are passed from parent to child and may come in different forms. Genes carry information that determines physical characteristics, such as skin and eye color. Genes also can affect your health.

Everyone has a gene called *APOL1* (Apolipoprotein 1). This gene can affect how your kidneys work. *APOL1* comes in different forms. Some forms of *APOL1* can protect West Africans (where most African Americans/Blacks come from) from African Sleeping Sickness. However, those same forms of *APOL1* increase the chance of having CKD. These forms of *APOL1* are more common in African Americans and Blacks.

There is a blood test that can detect *APOL1* forms that increase kidney disease risk. But it is unclear whether patients should be tested for them because many questions have not been answered.

## What Is Known about People with APOL1 Risk

- 13 in 100 African American and Blacks will have forms of *APOL1* that increase risk of CKD
- 2 to 3 of the 13 people with *APOL1* risk will get CKD
- Many people with *APOL1* risk and CKD will get kidney failure
- Kidney disease may start at any age



## What Is Not Known about People with *APOL1* Risk

- Among those with the *APOL1* risk, we do not know who will get CKD and who will not.
- We do not know if taking good care of blood pressure lowers the chance of CKD.
- We also do not know if taking good care of blood sugar (diabetes) lowers the chance of having CKD.
- We do not know if there are other things that can be done to lower the chance of developing CKD.

These unknowns raise a number of questions that include: Should all African American and Blacks be tested for *APOL1* risk? If not, who should be tested? Should people who want to donate a kidney be tested for *APOL1* risk? Should people with *APOL1* risk be allowed to donate a kidney?

These and other questions cannot be answered based only on facts. They involve judgments about possible harms and benefits that might come with testing. So, input is needed from people who are most likely to have *APOL1* risk or get CKD. We need to hear from you.

## Thank you for agreeing to be in a Community Conversation

- ❖ There will be Community Conversations in Seattle, Washington; Jackson, Mississippi; and Nashville, Tennessee.
- ❖ Each meeting will last 2 days, and take about 5 hours each day.
- ❖ You will have plenty of time to learn about the issues, ask questions, and talk with others.
- ❖ Food will be served at breaks so we can keep talking.
- ❖ People will be paid \$250.00 for completing the 2-day, 10-hour meeting.
- ❖ After the meeting, we will write a report. You will have the chance to review the report and suggest changes. You will get a copy of the report.
- ❖ The reports from all three meetings will be put together in a final report that will then be given to leaders in kidney care and policy making as well as patient groups at a national meeting in March 2018.
- ❖ This study is paid for by the National Human Genome Research Institute (NHGRI) of the National Institutes of Health.



**Polling Questions  
ROUTINE PATIENT CARE**

**ROUND 1**

	<b>AGREE</b>	<b>DISAGREE</b>	<b>UNSURE</b>
Offer <i>APOL1</i> testing to African American and Black patients only if they have signs of kidney disease, such as protein in the urine	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Offer <i>APOL1</i> testing to African American and Black patients who have kidney disease risk factors (for example, high blood pressure) but no signs of kidney disease	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Offer <i>APOL1</i> testing to all African American and Black patients	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Do not offer <i>APOL1</i> testing to any patients	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Use the resources for purposes other than <i>APOL1</i> testing For example _____	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
(round 2 identical questions)			

**Polling Questions  
KIDNEY TRANSPLANT CARE**

**ROUND 1**

	<b>AGREE</b>	<b>DISAGREE</b>	<b>UNSURE</b>
Test kidneys of deceased donors for <i>APOL1</i> risk	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Offer <i>APOL1</i> testing to potential living donors	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Require living donors to be tested for <i>APOL1</i> risk	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Do not allow living donors with <i>APOL1</i> risk to donate a kidney	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Do not use <i>APOL1</i> testing in transplantation decision-making	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
(round 2 identical questions)			