

Service:
Living Kidney Donor Team

APOL1 Gene Testing

For people who want to donate a kidney

This leaflet should provide you with more information about the test, why it is being recommended, and what it involves.



What are genes?

Genes carry the instructions for how we look and how our bodies work. We inherit our genes from our parents. Genes are made up of small pieces of DNA.

There are lots of different versions of each gene. For example, there is a gene for tongue curling. Some versions of this gene mean people can curl their tongue. Other versions of this gene mean people can't curl their tongue. Whether someone can curl their tongue depends on which type of tongue curling genes they've inherited from their parents.

Differences in some genes can put us at risk of getting some diseases.

What is the APOL1 gene?

Genes all have different names. One gene is called the APOL1 gene. APOL1 is short for 'Apolipoprotein L1'. Everyone has two copies of the APOL1 gene. There are three different versions of the APOL1 gene. These are called G0, G1 and G2. The G1 and G2 genes are much more common in people of African or Caribbean heritage. These genes help people to survive an infection called 'sleeping sickness' that is common in Africa.

The G1 and G2 genes have been found to carry a higher risk of kidney disease than the G0 version.

People who carry two copies of the higher risk genes have an increased risk of developing kidney disease in the future.

The picture shows who is at an increased risk.



G0 G0

Jonathan has
0 high-risk APOL1
genes

**No increased risk
of kidney disease**



G1 G0

Chrissy has
1 high-risk APOL1
gene

**No increased risk
of kidney disease**



G1 G1

Anthony has
2 high-risk APOL1
genes

**Increased risk of
kidney disease**

What is the test?

We do a simple blood test to find out which genes someone is carrying.

What if the test shows I do not have an increased risk of kidney disease?

If the test shows you don't carry two copies of the high-risk genes then you can carry on with other tests to see if you can donate one of your kidneys.

What if the test shows I have a higher risk of kidney disease?

If the test shows you have two copies of the high-risk genes then your doctor will talk to you about whether it is safe for you to donate a kidney. Research has suggested that 3 out of 5 people with two high-risk genes develop kidney disease after donating a kidney.

Younger people will be advised that this risk is too high to donate a kidney.

If you have two copies of the high-risk genes but do not donate a kidney, you are unlikely to develop kidney disease. 1 out of 5 people with higher risk genes develop kidney disease. This means that 4 out of 5 people who have higher risk genes DO NOT get kidney disease.

Do I have to have the test?

No. If you decide not to have the test you may be advised that you cannot donate one of your kidneys. This is because if you have the higher risk genes, donating a kidney would put you at a high risk of developing kidney disease. Doing the test will give you and your medical team more information about the risks of donation, to help you decide if kidney donation is right for you.

What can I do to help my kidneys to stay healthy?

There are things you can do to keep your kidneys healthy:

- **Eat healthily and stay hydrated** – try not to eat too much salt or fatty food.
- **Stay a healthy weight and keep active**
- **Check your blood pressure** – if your blood pressure is high you may need treatment to bring this down
- **Don't smoke**
- **Don't drink more than 14 units of alcohol a week**

References

- Doshi M, Ortigosa-Goggins M, Garg A, et al. APOL1 Genotype and Renal Function of Black Living Donors. *JASN*. 2018;29(4):1309-16
- Dummer PD, Limou S, Rosenberg AZ et al. APOL1 Kidney Disease Risk Variants: An Evolving Landscape. *Semin Nephrol* 2015;35(3):222-36

**PATIENT
APPROVED** 

How to contact us:



Living Kidney Donor Team

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If you or the individual you are caring for need support reading this leaflet please ask a member of staff for advice.

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