

### **Is the oral contraceptive or hormone replacement safe?**

The use of the oral contraceptive pill (OCP) or hormone replacement therapy (HRT) is associated with a small increase in the risk of thrombosis in everybody. This risk is increased if you have Factor V Leiden. We don't advise the use of the pill or HRT if you have Factor V Leiden and have had a thrombosis. If you have Factor V Leiden but have never had a thrombosis, the decision is more difficult. We would need to make a decision based on an assessment of all your risks of thrombosis.

### **What is the risk in pregnancy?**

Pregnancy itself carries a small increase in the risk of thrombosis. If you have had a previous thrombosis and have Factor V Leiden we recommend treatment with low dose heparin during and for a few weeks after pregnancy. If you have factor V Leiden but have never had a thrombosis, then in most cases, heparin will not be prescribed during pregnancy.

# **Royal United Hospital Bath**

**Department of Haematology**

## **Factor V Leiden Information for Patients**

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## Thrombophilia caused by Factor V Leiden

The abnormality of Factor 5 clotting protein usually called Factor V Leiden is the commonest inherited problem associated with an increased risk of thrombosis.

First described in 1994 in Leiden in Holland, the abnormal factor V protein is resistant to being broken down by the anti-clotting mechanisms of the body. This means that Factor V builds up in the blood and causes clotting faster than usual.

This abnormality is common in Western Europeans and is seen in about 55 (1 in 20) of the population. In some parts of the world it is even more common e.g. Southern Sweden and Greece (up to 15% of the population) but is quite uncommon in people of African descent.

### How is Factor V Leiden inherited?

We have two Factor V genes – one from our mother and one from our father. Therefore there are three possibilities:

- We inherit normal Factor V genes from each parent (no increased risk of thrombosis)
- We inherit one normal gene from one parent and one abnormal from the other. This is known as being *heterozygous* and half the factor V produced in our body will be abnormal.
- If we inherit the abnormal gene from both our parents we are *homozygous* and all the factor V the body produces will be abnormal.

Therefore if a parent is *heterozygous* they will have one abnormal and one normal gene. This means that their children will have a 50% chance of inheriting the abnormal gene.

If both Factor V genes are abnormal the patient is *homozygous* and one copy of the abnormal gene will be passed on to all their children.

## Why is Factor V Leiden important?

Factor v Leiden is associated with a small increase in the risk of venous thrombosis (clots in the veins), especially in the legs. This risk is highest in patients who have two genes affected (*homozygous*). Some doctors believe that it may contribute occasionally to recurrent miscarriages and high blood pressure in pregnancy. There is also some evidence of an increased risk of heart disease. For this reason we encourage patients with factor V Leiden to avoid other risk factors for heart disease such as high blood pressure, smoking and high cholesterol.

### Treatment

Most people with Factor V Leiden require no specific treatment. Your doctor can advise you about ways to reduce the risk of thrombosis, such as during long haul flights. Should you require a surgical procedure or long stay in hospital you may need low dose heparin injections to prevent clots. If you have two abnormal Factor V genes, another thrombophilia in addition to factor V Leiden or repeated episodes of thrombosis, we may recommend lifelong warfarin treatment.

### Should my Family be tested?

Since Factor V Leiden has a tendency to run in families, we usually recommend that if one member of a family is found to have Factor V Leiden, other members of the immediate family should be tested. Although specific treatment is not required in affected family members, simple precautions in situations of increased risk are advised. Because the risk of thrombosis in children with Factor V Leiden is so small, we do not recommend testing in the under sixteens.