

PATIENT INFORMATION

Factor V Leiden

What is factor V Leiden?

This is the name given to a variant form of one of the normal clotting factors found in the blood (factor V). It was discovered in the Dutch city of Leiden.

Why is factor V important?

Factor V helps to make the blood clot but its action is controlled by another blood factor known as protein C which normally breaks down factor V. The factor V Leiden variant is relatively resistant to the action of protein C. This makes clots more likely to form in the veins. Some people refer to factor V Leiden as 'APCR' – Activated Protein C Resistance.

How common is factor V Leiden?

About 1 in 20 of Northern European people carry the factor V Leiden variant gene. Other racial groups seem to be much less affected.

Where does my factor V Leiden come from?

You would have been born with this tendency to form clots and either your father or mother is likely to have passed it on to you.

When is thrombosis of the veins likely to occur?

It can occur at any time although it is rare in childhood. The degree of risk increases with age. Factors that increase the risk include:

- Being overweight
- Smoking
- Prolonged immobilisation
- Having an operation
- After an accident
- The combined oral contraceptive pill
- Hormone replacement therapy
- Severe illness such as cancer
- Presence of any other inherited causes of a clotting tendency

What is the risk of thrombosis with factor V Leiden?

Information is still being gathered about this. It is thought that if a person inherits the factor V Leiden gene from one parent there is about a five to ten fold increase risk compared to normal, of having a thrombosis in the veins. If factor V Leiden is by any chance inherited from both parents the risk is higher. Blood clots are still rare however and the large majority of people with factor V Leiden will never have any associated problem.

Pregnancy

There is growing evidence that the factor V Leiden gene can be associated with obstetric complications such as recurrent miscarriage or stillbirth. Your doctor will advise you about this and will be able to discuss a number of possible treatments.

Having found out I have the factor V Leiden gene what should I do?

The first thing to say is that you should not see yourself as ill or “abnormal”. Your clotting tendency may not cause you any problems but you can take steps to reduce the risk of thrombosis in the future by doing the following:

- Lead a physically active life
- Eat a healthy diet and avoid becoming overweight
- Avoid smoking
- Avoid prolonged immobility during long journeys
- Take advice from your doctor if you are planning a long aeroplane flight (longer than 8 hours).
- Avoid certain types of contraceptive pill
- Take advice before starting hormone replacement therapy

Liaising with your doctor if you are entering a high risk period for thrombosis such as major surgery, immobility or pregnancy. Your doctor will advise you if you need special hosiery or medication.

Should other members of the family be tested?

Guidelines recommend that testing for heritable thrombophilia is not indicated in unselected patients presenting with venous thrombosis. Testing of selected patients may be helpful in long term management.

If you have any questions about the information in this leaflet, please contact:

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For further assistance or to receive this information in a different format, please contact the department which created this leaflet.