

Patient information

Factor V Leiden

Haematology Liverpool

What is Factor V Leiden?

Factor V Leiden is an inherited Blood clotting disorder. It is also a form of a thrombophilia condition.

Factor V is a protein required for the blood to clot properly. People with factor V Leiden have a genetic defect of this protein. This increases the chance of developing blood clots. The different gene that makes the factor V Leiden protein is inherited from one or both parents.

However, it is estimated that 95 % of people with Factor V Leiden will never develop a clot.

How does Factor V Leiden affect blood clotting?

If you are injured, your body needs to stop bleeding by forming a clot. Once bleeding stops the clotting needs to be turned off.

You have different proteins that do this work.

Factor V is one of the proteins needed to make the blood form a clot. The clotting action of factor V is controlled by another protein called activated protein C. This stops the blood forming clots by turning off the factor V.

Factor V Leiden works very well in in the clotting pathway and speeds up the clotting, but it is resistant to the Activated Protein C and cannot be turned off easily. As a result, the clotting goes on for longer. Therefore, people with factor V Leiden have an increased risk of developing blood clots.

What is the cause of Factor V Leiden?

Genes are the sequences that are the body's means of storing the information needed to produce chemical substances within the body.

There are two copies of the Factor V gene: one from our mother and one from our father. If one of these inherited genes is different this makes the factor V Leiden protein.



Heterozygous Factor V Leiden

If you have inherited one factor V Leiden gene from one parent, you have heterozygous Factor V Leiden.

- This happens in about five out of 100 people of Caucasian descent.
- Slightly increases risk of developing a blood clot.

Homozygous factor V Leiden

If you have inherited two Factor V Leiden genes, you have homozygous Factor V Leiden.

- You have inherited one factor V Leiden gene from your mother and one from your father.
- This happens in less than one out of 100 people.
- There is more risk of developing a blood clot.

How is it diagnosed?

It is diagnosed by a blood test, called a thrombophilia screen. This can be done at any time, but you need to be off anticoagulation.

Can I pass on Factor V Leiden?

Yes, you can pass this gene on to your children

- If you have the heterozygous type, there is a 50% chance that your child will inherit the factor V Leiden gene from you. There is also a 50% chance that your child will inherit your normal Factor V gene.
- If you have Homozygous Factor V Leiden, there is 100% chance that if you have children, they will inherit one copy of the Factor V Leiden gene. They will have either heterozygous or homozygous, depending on whether the gene passed down from their parent is normal (Factor V) or abnormal (Factor V Leiden)

Factor V Leiden is an inherited disorder. If you have siblings, they may have inherited this gene.

You may be more at risk of developing a blood clot. This usually occurs in the veins, especially of the legs or lungs. A blood clot in the legs is called Deep Vein Thrombosis (DVT). In the lungs it is called a pulmonary embolism.

- Signs of a DVT: swelling /redness/pain in your calf or thigh.
- Signs of PE: Shortness of breath, chest or shoulder pain, and cough with blood-stained sputum.

When am I more at risk of developing problems?

It is Important to note that not everybody with Factor V Leiden will develop a blood clot.

It is very unlikely to develop clots in childhood. The incidence of developing a clot increases with age:

- Those in their twenties have a risk of one in 100,000 per year.
- By age 40, this risk is one in 1,000 per year.
- By age 80, the risk is one in 100 per year.

Risk factors

- Over 40.
- If you smoke.
- If you are overweight.
- If you are having surgery.
- If you have reduced mobility.
- During pregnancy.
- If you take treatments containing Oestrogen (such as HRT or the combined contraceptive pill).
- Cancer.
- Had a clot in the past.
- Long journey /long haul flights.
- Becoming dehydrated.

What happens if I develop a blood clot?

You will be referred to the anticoagulant clinic and treated with an anticoagulant; this will be for three to six months and reviewed at this point. You will be monitored by the anticoagulant team and your treatment will be fully discussed with them.

Please note: if you have never had a clot you don't need to be on an anticoagulant

How can I reduce my risk of developing a blood clot?

- Stop smoking.
- Lose weight.
- Inform your doctor about your condition if you're having surgery.
- Avoid long periods of immobility.
- For long haul flights, you should walk around if you can, keep well hydrated and avoid alcohol. Wear compression socks or flight socks.
- Eat a balanced diet.
- Stay mobile.
- Keep hydrated.
- Talk to your GP/Nurse / haematology team.

Information for Women with Factor V Leiden

What if I want to take the contraceptive Pill?

Women taking the combined (oestrogen and progesterone) contraceptive pill are four times more likely to develop blood clots. The presence of factor V Leiden increases the risk further. It is recommended that women with Factor V Leiden use an alternative form of contraception, if possible, especially if they have already had a blood clot or have first degree relatives with blood clots. Please discuss this further with your Doctor / Nurse / health care professional.

What If I want Hormone Replacement Therapy (HRT)?

HRT approximately doubles the risk of developing a clot. In real terms this is a small risk. For many Women the benefits of HRT outweigh the risks. There is some suggestion the HRT patches have a slightly lower risk for blood clots than tablets. Please discuss this with your doctor.

What if I become pregnant?

If you have already had a clot: You will need anticoagulant medication during pregnancy in the form of injections. The highest risk period is usually during the third trimester and six weeks after delivery. Please inform your Doctor/ Midwife / haematology team if you are planning to get pregnant or as soon as you know.

If you have never had a blood clot: Anticoagulant medication may not be necessary during pregnancy. Please discuss this further with your Health care team.

If you develop symptoms of a DVT or PE during pregnancy you should seek medical attention immediately.

Four percent of Women have Factor V Leiden but have very few clots during pregnancy. There has been some research to suggest that women with factor V Leiden gene may have a greater risk of miscarriage, please discuss this further with your Doctor / Specialist Nurse

Feedback

Your feedback is important to us and helps us influence care in the future.

Following your discharge from hospital or attendance at your outpatient appointment you will receive a text asking if you would recommend our service to others. Please take the time to text back, you will not be charged for the text and can opt out at any point. Your co-operation is greatly appreciated.

Further information

Haematology Liverpool Patient Line

Tel: 0151 706 3397

Text phone number: 18001 0151 706 3397

External Websites

www.thrombosisuk.org

All Trust approved information is available on request in alternative formats, including other languages, easy read, large print, audio, Braille, moon and electronically.

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