Factor V Leiden

This is by far the most common inherited ‘sticky blood’ which increases the risk of blood clots, most common in people of European and Middle Eastern origin. It is very rare in those of Asian and African origin.

What is Factor V Leiden?
This form of sticky blood is due to a change in the gene for Factor V which makes someone more prone to deep-vein thromboses (blood clots in the legs. The risk of blood clots in the legs in those with heterozygous Factor V Leiden (see below) is eight times more than those without it. Those with two gene changes have a risk of blood clots that is 80 times greater than those who do not have it.

Why is it called Factor V Leiden?
It is named after the town of Leiden, in Holland, where it was originally discovered.

How is Factor V Leiden inherited?
Factor V Leiden is inherited in an ‘autosomal dominant way’. This means that if one parent has it, there is a 50:50 chance (1 in 2 chance) that any child will inherit it. Having one change in the gene of Factor V Leiden is known as heterozygous Factor V Leiden. Two changes are known as homozygous Factor V Leiden.

How does Factor V Leiden make blood more prone to venous thrombosis?
Factor V helps in promoting blood clotting. To stop blood from clotting, a natural blood thinner known as protein C breaks down Factor V to stop the clot getting bigger. If you have Factor V Leiden, the factor V molecule is relatively resistant to being broken down. Because of this, the clotting process goes on for longer.

Does Factor V Leiden increase the risk of arterial thrombosis such as heart attacks or strokes?
There has been a lot of work done in this area. Factor V Leiden does not increase the risk of arterial thrombosis. So, there is no increased risk of heart attacks or strokes.

When can thrombosis of the veins happen?
If you have Factor V Leiden, you will not just get a thrombosis in one of your veins. There must be other risk factors.

One of the risk factors is getting older. As we get older our blood gets stickier. This means it is very rare for children to have blood clots but quite common in old age.

Other factors are:

- not being able to move around much;
- having an operation, especially surgery on the legs, hips, or pelvis;
- being pregnant and the six weeks after pregnancy;
- severe illnesses such as inflammatory bowel disease or cancer;
- if you have had an accident;
- being overweight;
- using the combined oral contraceptive pill;
- using hormone replacement therapy, and
- having another thrombophilia.
What is the risk of having a venous thrombosis with Factor V Leiden?
Research suggests the risk of suffering a venous thrombosis is eight times greater for people who have Factor V Leiden than those who don’t. To give a sense of proportion, the risk of having a venous thrombosis is still very small, and most people with Factor V Leiden will not have a venous thrombosis. (If they did, 5% of the population would have had one!). Nevertheless it seems sensible that at times of increased risk (such as after surgery), preventative measures are taken.

Are there any advantages in having Factor V Leiden?
This has been the subject of a lot of research recently. For a genetic change to be as common as appearing in one in 20 of the population there should be a survival advantage. It seems that the advantage of having Factor V Leiden is that people bleed less when they have a wound. Less than 100 years ago women often died from bleeding after childbirth. Women with Factor V Leiden will bleed less in this situation and so stand a better chance of survival than those without. And, with modern obstetric care it is very rare for women to die from bleeding in childbirth and so this is no longer an issue.

I have just found out that I have heterozygous Factor V Leiden, what should I do?
Firstly you need to remember you are not ill or abnormal. All that has happened is that you are now aware that you have an increased risk of venous thrombosis.

You can reduce the risks of venous clots in the future by following the advice below.

- Lead a physically active life.
- Eat healthily and avoid becoming overweight.
- Avoid sitting or lying around for long periods when ill or travelling.
- If you are a woman, get medical advice about contraception and hormone replacement.
- If you are pregnant, mention that you have Factor V Leiden to your midwife and obstetric.
- Speak to your doctor if you are at high risk of thrombosis (for example, you are going to have major surgery, not be able to move around much or if you are pregnant).
- Avoid smoking.

Should other members of the family be tested?
This is recommended for close blood relative (brothers and sisters, sons and daughters) as there is a 50:50 chance that each one may be affected. Because people with Factor V Leiden do not tend to have problems until they are adults, it is not usual to test children until they can have blood taken without distress to them and they are old enough to understand why the blood sample is being taken (usually after the age of 13).

What tests are carried out to detect Factor V Leiden?
In the laboratory there are two tests. The first is known as activated protein C resistance (APCR). This is to test for the effect of Factor V Leiden on the clotting system. The most effective test is a genetic test, which looks for the change of Factor V Leiden in the genes. APCR is usually performed first as a screening test.

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