fact sheet

Factor V (Five) Leiden Mutation

Overview

What is Factor V Leiden Mutation?

Factor V Leiden is a common change in a gene that controls a protein called Factor V. Factor V is a protein involved in blood clotting and the Factor V Leiden gene change (also called mutation) is linked to an increase risk of blood clots.

How did I get Factor V Leiden mutation?

Factor V Leiden mutation is an inherited condition (i.e. from your parents). We inherited one copy of each gene from each of our parents. One (or both) of your parents will have passed the Factor V Leiden mutation on to you and you may pass the condition onto your children.

How common is the Factor V Leiden Mutation?

Factor V Leiden mutation is common - it occurs in about 1 in every 20 - 25 people in Australia. This mutation is more common than many mutations. Because the mutation is very common, it has been suggested that Factor V Leiden may have some benefit.

What are the main problems with having the Factor V Leiden mutation?

The main problem with having Factor V Leiden mutation is having an increased risk of developing blood clots. Blood clots can occur in blood vessels and can sometimes travel to different parts of the body including the lungs. Having Factor V Leiden increases your risk of having a blood clot.

If you have one copy of the Factor V Leiden mutation (also called being a heterozygote for this gene), you are at around 8 times more at risk of developing a blood clot compared to someone your age who does not have this gene change. If you have two copies of the Factor V Leiden mutation (called homozygote), you have approximately 80 times the risk of developing a blood clot.

Am I going to get a blood clot because I have this mutation?

Most people with one copy of the Factor V Leiden mutation DO NOT develop blood clots. Blood clots usually only develop when there are other "risk factors" for blood clots. Blood clots develop when the circulation of the blood flow is reduced (e.g. after long flights, after surgery etc.) or in people with other serious medical conditions such as cancer or heart failure.

What about pregnancy and the use of hormones / oral contraceptive pills?

Both pregnancy and the use of the pill or hormone replacement therapy (HRT) after menopause can increase the risk of developing a blood clot. Women on the pill have around a 3 - 4 fold increased risk of getting a blood clot compared to other women who are not on the pill. Women who are on HRT have around a 2 - 3 fold increased risk in getting a blood clot. If women also have one copy of the Factor V Leiden mutation, these risks increase to around 35 times the risk of having a clot on the pill and 15 times the risk of having a clot on HRT. These risks sound high but clots are still relatively uncommon in the community. The risk of having the pill or HRT should be discussed with your doctor.

Are there any benefits of having Factor V Leiden mutation?

Because the people with Factor V Leiden have blood that clots more easily, it has been suggested that this may be beneficial during times during bleeding episodes (e.g. during menstruation or after childbirth). This is only a theory and there has not been any studies to confirm this theory.

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Is there any treatment for Factor V Leiden?

No treatment to change genes is currently available. Most people who have Factor V Leiden mutation do not need any treatment but need to be careful at times when the risk of getting a blood clot may be increased (e.g. after surgery, during long flights etc). [See information sheet on Clots and Flights].

Sometimes people with the Factor V Leiden mutation may need to go on blood thinning medication to reduce the risk of developing blood clots. This will depend on lots of other factors including a past medical history of clots or a family history of blood clots.

Is there anything else I should do to protect my self against getting blood clots?

Maintaining a healthy weight, stopping smoking, staying active and keeping any other medical conditions under control should also help you protect against getting any blood clots. You should tell your doctor or surgeon that you have the Factor V Leiden mutation before any operations or prolonged periods of bed rest.

Should my family be tested for Factor V Leiden?

Testing is easily done - a simple blood test is all that is required. Most people think testing is a good idea but you and your family should think carefully about testing for the Factor V Leiden mutation. There may be some change to health and life insurance policies. Clots in children are very uncommon so it is probably best to wait until children are older (usually in their late teens) and can decide if they want the testing performed.

Resources used in producing this patient information

- Investigation and management of heritable thrombophilia. British Journal of Haematology 114 (3), 512-528.
- Factor V Leiden: An Overview Clinical Laboratory Science. Fall 2006.Vol.19, Iss. 4; pg. 218, 4 pgs

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FURTHER QUESTIONS?

The information presented in this fact sheet is intended as a general guide only.

Patients should seek further advice and information about Factor V Leiden Mutation and their individual condition from their treating haematologist or doctor.

For additional information about blood disorders and their treatment, or to contact one of our specialist haematologists, visit the Melbourne Haematology website: www.melbournehaematology.com.au