

YOU HAVE HETEROZYGOUS FACTOR V LEIDEN (FVL)

PATIENT INFORMATION SHEET

WHAT IS HETEROZYGOUS FACTOR V LEIDEN (FVL)?

Factor V (5) helps your blood clot, so having too much encourages clots.

You may have inherited the factor V Leiden genetic mutation from your mother and/or father. **Heterozygous** means that you have one gene passed down from your mom or your dad. About 1 in 20 people have this. **Homozygous** means that you have 2 genes, one from your mom and one from your dad. This is very rare.

Thrombophilia is a tendency to form excessive blood clots, also called thrombosis (see below). Factor V Leiden is a type of thrombophilia that interferes with your body's ability to form clots. It is a rare disorder that occurs in about 3 in 1000 people and is a strong risk factor for clots.

RISK OF CLOT PER YEAR

People without factor V Leiden	1 in 1000 (0.1%)
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People with factor V Leiden gene mutation	
• Risk of first-time clot	~3-10 in 1000 (0.3 – 1.0%)
• Risk of clot if taking estrogen (birth control or hormone replacement)	~5 in 1000 (0.5%)
• Risk of clot during pregnancy	~21 in 1000 (~2%)
• Risk of clot during surgery	~18 in 1000 (~2%)

WHAT IS THROMBOPHILIA SCREENING?

- Blood tests that can look for the presence of a thrombophilia gene or a lower level of the specific protein or protein activity. These genes can be passed on through the family.

THROMBOSIS

Thrombosis is a medical term for a blood clot.

A deep vein thrombosis (DVT) is a blood clot that occurs most commonly in the deep vein of the leg but can occur in any vein in the body.

If left untreated, DVT can move to the lung where it causes pulmonary embolism (PE). Pulmonary embolism causes shortness of breath, chest pain, and tiredness. Once DVT has moved to the lung, the clot is stuck there and cannot move.

Because blood clots in the lungs cannot move, PEs do not cause strokes or heart attacks. About half the time people with DTV also have PE.



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WHO SHOULD BE TESTED?

- Most people do not need testing as the results will not affect or change your treatment.
- Sometimes testing is done at the wrong time and results can be confusing. For example some blood tests cannot be done if you are taking an anticoagulant (also called a blood thinner).
- Thrombophilia testing is expensive.
- Life insurance may be more expensive or harder to get if you test positive for a thrombophilia.

WHAT IF I HAVE A THROMBOPHILIA?

- Having a thrombophilia may slightly increase your chance of forming a first-time blood clot. This is still a small chance.
- If you have a blood clot, usually other things that cause blood clots are more important than thrombophilia.
- If you are pregnant or on estrogen (birth control or hormone replacement), talk to your healthcare professional to see if this is important.
- If you or your family has had clots, talk to your doctor about options for birth control or hormone replacement therapy.
- Talk to your healthcare provider if you are or plan to become pregnant. You may need an anticoagulant to prevent a clot during pregnancy.
- You should receive an anticoagulant after surgery to prevent blood clots

WHAT ABOUT MY FAMILY?

There is no need to test everyone in your family.

Having a close relative with a blood clot increases your chance of forming a blood clot, regardless of thrombophilia testing. It is important for family members to know the symptoms of blood clots, and things that can increase their risk, so they can talk to their healthcare professional if these happen to them.

TAKE AWAY MESSAGE

- Thrombophilia testing does not change how most people are treated for blood clots.
- Testing for thrombophilia should not be done in most people.

