



ABOUT HUGHES SYNDROME

Diagnosis: how to get tested

Hughes/antiphospholipid syndrome is diagnosed from a combination of a positive blood test and symptoms.

If you are displaying symptoms of Hughes/antiphospholipid syndrome, book an appointment with your GP and ask to be tested for antiphospholipid antibodies (aPL).

It is important to let your doctor know about any previous blood clotting or pregnancy problems and also more low-grade symptoms such as headaches, migraine, visual disturbances, dizziness, arthralgia (joint pain) and fatigue. Family history is crucial too, so remember to list any immediate family with an autoimmune disease or history of thrombosis.

The blood tests for aPL will be taken either at your surgery or local hospital. There are three different tests used to diagnose Hughes/antiphospholipid syndrome but they are all looking for antiphospholipid antibodies (aPL):

- Anticardiolipin antibodies (aCL)
- Lupus anticoagulant (LA)
- Anti-beta2-glycoprotein-1 (anti-B2GP1)

The reason for the three tests is that they measure aPL in different ways which means that one test alone could miss the diagnosis. The LA is a very confusing name and is not a test for lupus.

If any of the tests are positive, it will be necessary to repeat them again because harmless aPL can be detected in the blood for brief periods in association with a wide variety of infections such as chickenpox, and certain drugs including antibiotics and some blood pressure tablets.

For this reason, the tests should be repeated after 6-12 weeks. If someone has only one positive test and it quickly becomes negative again, then it is unlikely they have Hughes/antiphospholipid syndrome.

All laboratories differ in the way they measure their tests so it is impossible to provide guidelines indicating the positive and negative ranges. However, your results should show whether you are negative or positive according to your laboratory's classification.

Making a diagnosis can be complicated due to a lack of clear guidelines and the fact that some symptoms caused by Hughes/antiphospholipid syndrome can also mimic other conditions such as vertigo, MS and Alzheimer's. Therefore, it is likely you will be referred to a specialist for the final diagnosis. The particular type of specialist can vary in hospitals throughout the UK, but is usually either a haematologist or a rheumatologist. Most early pregnancy units will be proficient in treating women with Hughes/antiphospholipid syndrome.

Evidence shows that early diagnosis can make a big difference to the lives of those with Hughes/antiphospholipid syndrome so, as the tests are relatively cheap (less than £100), it makes sense to see your GP if you are experiencing symptoms.