Diagnosing anti-phospholipid syndrome (Hughes syndrome)

This leaflet has been written to provide you with information about testing for obstetric antiphospholipid syndrome. If you are unsure about anything, please contact the screening coordinators.

Introduction

Antiphospholipid syndrome (APS) is a disease caused by the body's immune system causing an increased tendency of the blood to clot. APS is associated for some patients with SLE (systemic lupus erythematosus), another autoimmune condition, but can also occur on its own. In some patients the problems occur mainly in pregnancy, resulting from damage to the baby's placenta, in which case we call this obstetric APS. Obstetric APS causes an increased risk of pregnancy loss, reduced growth of the baby, premature delivery or a condition called pre-eclampsia where the mother develops high blood pressure. Patients with obstetric APS are at increased risk of venous blood clots and will be recommended to receive preventative blood thinning injections during pregnancy, and generally also to take low dose aspirin.

In some patients APS causes venous thrombosis or arterial thrombosis (e.g. a stroke), a condition called thrombotic APS. An individual patient may have either obstetric APS or thrombotic APS or both.

Testing for APS

Testing for APS in the laboratory is done with blood tests which look for the presence of several different antibodies:

- Anti-cardiolipin IgG: laboratory reference range 0 - 9.9 Units
- Anti-cardiolipin IgM laboratory reference range 0 - 9.9 Units
- Anti-β2-glycoprotein-1 IgG laboratory reference range 0 - 6 Units
- Anti-β2-glycoprotein-1 IgM laboratory reference range 0 - 9.9 Units
- An antibody-related change in the way blood clots in a test tube called a lupus anticoagulant

Interpreting these tests is quite complex and a significant proportion of the normal population, up to around 5 or 10 out of 100 patients, will have detectable antibodies although often these are at low level and come and go over a period of weeks. To diagnose APS the antibody needs to be at a high enough level and also persist over at least 12 weeks.

For the antibodies to be high enough to make a clear diagnosis of APS the main American and European Rheumatology expert groups recommend the antibody level should be at least moderate (> 40 Units).

For the lupus anticoagulant laboratories will generally report the test as positive or negative, although some results reported as positive may be weak and it is advised that the significance of any positive result is discussed with a Haematologist.

Diagnosing Obstetric APS

The Diagnosis of APS is based on combination of laboratory tests as above and your medical history. If blood tests confirm you have obstetric APS, your medical history will be carefully assessed to check whether you have experienced any previous symptoms that may be caused by APS.

A diagnosis of APS can usually be confirmed if you have significantly positive laboratory tests on 2 occasions at least 12 weeks apart, and also any of:

- Three or more unexplained early miscarriages before week 10 of your pregnancy
- One or more unexplained late miscarriages at or after week 10 of your pregnancy
- One or more premature births at or before week 34 of your pregnancy
- Pre-eclampsia with severe symptoms at or before week 34 of your pregnancy

What medication should I have in pregnancy if I have APS?

We advise women who have had two positive tests, and therefore have this condition, to take aspirin and a low molecular weight heparin (by injection) once they have a confirmed live pregnancy, and to continue with injections until six weeks after the baby's birth. At the Royal Berkshire Hospital, we advise taking 150mg aspirin and Clexane (Enoxaparin) (the dose is calculated according to body weight). Aspirin can be started before the first scan.

More information is available from www.nhs.uk/conditions/antiphospholipid-syndrome/treatment.

For women who have had just one positive test before a new pregnancy is confirmed, you will be given individualised advice from the Obstetric team.

To find out more about our Trust visit www.royalberkshire.nhs.uk

Please ask if you need this information in another language or format.

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