new symptoms develop, and to let any new doctor you see (especially if surgery is planned) know about the condition.

What research is being done?

The antiphospholipid antibody syndrome was first described in 1983 and was not formally recognized as different from lupus until 1989. Current research is now defining some of the unusual manifestations of the disease, and researchers are also looking for new and better treatments. Some of the things being considered are safer and more convenient anticoagulants, and different ways in which clotting can be prevented. For instance, doctors are now interested in the possibility that drugs used to control cholesterol will also be beneficial in this disease. Ask for details of current research projects being done at this hospital.

Hospital for Special Surgery

Barbara Volcker Center for Women and Rheumatic Disease

For more information, please visit: **www.hss.edu**

Tel: 212.606.1461 **Fax:** 212.774.2374

Email: volckerctr@hss.edu

HOSPITAL FOR SPECIAL SURGERY



ANTIPHOSPHOLIPID ANTIBODY

This brochure was provided to you by the APS Foundation of America, Inc. with permission from Hospital for Special Surgery and the Barbara Volcker Center for Women and Rheumatic Disease.



www.apsfa.org

Barbara Volcker Center for Women and Rheumatic Disease

ANTIPHOSPHOLIPID ANTIBODY

What is antiphospholipid antibody?

Antiphospholipid antibody (aPL) is an abnormal blood protein (antibody) that causes blood clots and/or pregnancy losses. It is measured in several different ways, and is named for the way it is measured. In one test, it is called *anticardiolipin* antibody; in another, it is called *lupus anticoagulant*. It can also be called *antibody to beta-2-glycoprotein I*; sometimes, because of a technical aspect of the way the test is done, the antibody causes a *false positive* test for syphilis. (People with a false positive test do not have syphilis, or anything like it.) The term *antiphospholipid* refers to all of these tests.

If I have aPL, am I ill?

Many people have the antibody and are perfectly well. People do not have the *antiphospholipid antibody syndrome (APS)* if they have only developed symptoms, such as a blood clot or a pregnancy loss. Not everyone with aPL develops APS, but we can't tell who will and who will not.

If I have APS, do I have lupus?

About 1 of every 3 people with lupus has aPL, but only about half of people with APS have lupus. People with APS only have the *primary antiphospholipid antibody syndrome (PAPS)*. Those with lupus and APS have *secondary APS*. The

APS symptoms are the same for both, but people with secondary APS have additional symptoms due to lupus.

How did I get aPL?

No one knows why people develop aPL. Genetics are important (see below). Some infections can induce an antibody that superficially looks like aPL, so we suspect that aPL develops because of an infection, but we don't know which one. Treating for an infection does not get rid of the antibody.

What is going to happen to me?

If you have had a blood clot, you will be treated with an anticoagulant medication, such as warfarin (Coumadin) or heparin (including low molecular weight heparin). If you are pregnant, you'll be treated with one of the heparin preparations, since warfarin cannot be used in pregnancy. Many physicians also advise taking a baby aspirin tablet (81 mg) together with the anticoagulant medications. All of these medications can protect you against having further blood clots and can protect a pregnancy. If you have lupus as well, you will take medications specifically for lupus. Taking anticoagulant medications will stop you a bit from playing contact sports because of the risk of injury, but otherwise your life should not change very much. Some patients after many years of APS develop leaking heart valves. Your doctor will monitor your heart to see if this occurs. This problem does not require any treatment in advance.

Are other members of my family at risk?

Antiphospholipid antibody, like many of the autoimmune antibodies, tends to run in families. Although we know there is some hereditary component, second members of the family with APS are rare, so you shouldn't be excessively concerned for your parents, siblings, or children. If you are pregnant, you do not need to worry that the antibody will be transmitted to your infant.

Are there dangers for me to watch for?

The anticoagulant medications increase your risk of bleeding spontaneously, or of bleeding as a result of injury. Therefore you should be very careful when you use sharp objects or engage in contact sports. Your doctor will review with you any special precautions.

What can I do myself to help?

Unfortunately, we do not know of any special diet, exercise, or life style that will either help or hurt patients with APS. The best thing is to be very careful with your medicines, to tell your doctor if any