



# APS Foundation of America, Inc. Frequently Asked Questions

## Frequently Asked Questions about APS Answers to Questions 1-10

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Some answers were also provided by members of our [Medical Advisory Committee](#).*

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**1. Antiphospholipid Antibody Syndrome is described as an autoimmune disease, what does autoimmune disease mean?**

Our body's immune system fights infection by making antibodies. The antibodies work by finding invaders and coating them for removal. Sometimes the immune system gets confused and begins to make antibodies against the body itself. For example, in rheumatoid arthritis the immune system attacks the joints. Because of this, people with rheumatoid arthritis get joint pain and swelling. [Back to top.](#)

**2. What are Antiphospholipid Antibodies?**

Phospholipids are found in the blood and help keep the blood flowing without too much clotting or bleeding. Antibodies against phospholipid (antiphospholipid antibodies) mess up the normal balance between clotting and bleeding. The antibodies can increase a person's chance of having a blood clot. [Back to top.](#)

**3. Are there different forms of Antiphospholipid Antibody Syndrome?**

There are two forms of Antiphospholipid Antibody Syndrome. There is Primary Antiphospholipid Antibody Syndrome meaning it is a stand alone disease. There is also Secondary Antiphospholipid Antibody Syndrome. Many of those patients also have Lupus. [Back to top.](#)

**4. What is Catastrophic Antiphospholipid Antibody Syndrome?**

The catastrophic antiphospholipid syndrome is a very rare complication encountered in a subset of patients with antiphospholipid antibody syndrome. This rare syndrome is characterized by the development of multiple blood clots that block small blood vessels in several organs in the body. The organs most commonly affected by these small blood clots include the heart, lungs, nervous system, and kidneys. In many ways, this syndrome is similar to another rare disease, thrombotic thrombocytopenic purpura. [Back to top.](#)

**5. What causes Antiphospholipid Antibody Syndrome?**

*We have asked our Medical Advisory team this question over and over again, and none of them have the answer. We will continue to search for the answer of this one!* [Back to top.](#)

**6. How did I get these antibodies?**

Most the time, doctors do not know why some people get antiphospholipid antibodies. In a small number of people, an infection or drug caused the antibody. Some kinds of autoimmune diseases cause the antibody. In other cases, the antibody seems to run in families. The point of this study is to try and find the genes that cause APS. [Back to top.](#)

**7. Can you catch Antiphospholipid Antibody Syndrome?**

No, APS is not a contagious disease. [Back to top.](#)

## 8. **Is Antiphospholipid Antibody Syndrome a fatal disease?**

Antiphospholipid antibodies may be detected in individuals who are completely asymptomatic, but, in some patients, these antibodies may be associated with a rapidly progressive disorder that can be fatal. In addition, the blood clots that can be seen with these antibodies can be fatal, depending on how large they are or which blood vessels are affected. [Back to top.](#)

## 9. **How common is Antiphospholipid Antibody Syndrome?**

Women are more likely than men to be affected by Antiphospholipid Antibody Syndrome. Some estimates say that 75% to 90% of those affected are women. For example, it has been estimated by some doctors that one third of all of young strokes (defined as under the age of 50) are due to Antiphospholipid Antibody Syndrome. In obstetrics it is estimated by some doctors that up to 25% of all women with 2 or more spontaneous miscarriages have Antiphospholipid Antibody Syndrome. It is also believed by some doctors that 1 in 5 of all Deep Vein Thrombosis (DVTs), Pulmonary Embolisms (PEs) and even worse, amputations are caused by Antiphospholipid Antibody Syndrome. And it is believed that 10-15% of patients with Lupus also have Antiphospholipid Antibody Syndrome.

Still, with these statistics Antiphospholipid Antibody Syndrome is rarely discussed as a women's health issue and is often misdiagnosed as something else, therefore the total number of people effected and true statistics are really unknown. [Back to top.](#)

## 10. **Is the Antiphospholipid Antibody Syndrome hereditary, should my children be tested?**

APS is not hereditary in the sense in which we usually use that word--that is, the sense that we learned about in biology classes, where the precise "odds" of a trait being passed along to children can be calculated. Diseases or conditions with that sort of direct heredity are typically tied to one or more identified genes.

No cause for APS has yet been singled out. We do know that it belongs to the "family" of autoimmune diseases, in which antibodies to tissues of the patient's own body can be found--although how much mischief such antibodies may cause can vary considerably from one person to another. We also know that a tendency to some sort of autoimmune pattern (but not necessarily illness) tends to be familial; that is, when someone has one of these conditions, and their relatives are studied, a higher-than-usual presence of autoantibodies (not necessarily the same ones) is often found.

So the short answer to your first question is no. As to your second question: It may well be a good idea, since the testing simply involves analysis of a small quantity of drawn blood and will not harm your child. Do bear in mind that a diagnosis of APS isn't based on blood tests alone; there must also be clinical evidence. If your youngster is found to have one or both of the two antibodies associated with APS--anticardiolipin (ACL) or lupus anticoagulant (LAC)--that doesn't mean that your child either has APS or will ever have APS; many people have one or both and never become ill. Based on present knowledge, we can only say that we believe that such a finding in a healthy person may possibly signify some general susceptibility to autoimmune disease.

Are there particular steps you should take, if there is such a finding in your child, to protect him or her? Not really, since we haven't any idea exactly what may trigger these illnesses, but you might want to be especially careful to guard such a child from preventable diseases: Provide a good, balanced diet; steer your child away from greasy junk food that can encourage obesity and clog arteries prematurely; be sure that he or she receives all recommended immunizations; and be very sure that your child never smokes. [Back to top.](#)

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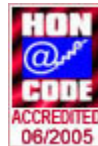


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