



APS Foundation of America, Inc. Frequently Asked Questions

Frequently Asked Questions about APS Answers to Questions 41-50

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

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41. Does APS Go Away? (S.P.B, MD)

Not really--although, as with the other autoimmune diseases, its signs and symptoms may vary from time to time. There may be only one clinical manifestation of APS--one episode of deep-vein thrombosis (DVT), for example--and then none ever again; it can't be concluded that the threat is gone. All laboratory values for which we routinely test may even become completely normal and may stay that way for an extended period of time; that can't be taken to mean that APS has vanished.

Remember that the recognition of APS as a disease entity is relatively recent, and that it was only in 1998, following an international conference on APS, that the preliminary diagnostic criteria were formulated. I stress the word "preliminary"; those criteria are based only on data established thus far--which include only two clearly identified antibodies, anticardiolipin (ACL) and lupus anticoagulant (LAC). Other factors--including other antibodies--will almost certainly be recognized in the future, as research goes forward.

Meanwhile, anyone who has been diagnosed with APS--and his or her physician--should assume the persistence of risk and continue to take appropriate protective measures. [Back to top.](#) - 4/25/06 ~ S.P.B, MD

42. If my antibodies become negative, should my doctor stop my anticoagulant? (S.P.B, MD)

Not necessarily. Sudden stopping of an anticoagulant could, under some circumstances, have extremely disastrous results. And as I have often cautioned medical students: While laboratory assays are invaluable both in diagnosis and in following treatment, the physician should treat the patient, not the lab test.

How to handle this situation is very much a clinical decision, based not only on blood values but on the doctor's experience, familiarity with the patient's history, examination and, to be frank, gut feelings (medicine is an art as well as a science).

It should be noted, too, that in such a situation, the physician may feel that further lab tests should be ordered, since there are additional proteins (unrelated to APS) involved in the clotting process. Assessing the levels of these elements may be helpful in clarifying the picture. [Back to top.](#) - 4/25/06 ~ S.P.B, MD

43. I am positive for anti-cardiolipin antibody [ACL] but have never had a confirmed clot. What are the chances that I will clot in the future? And what kind of treatment should I be on? (R.A.S.R, MD)

With regard to treatment, the first thing to do is work with your doctor to reduce or eliminate as many other risk factors for blood clots as possible. Stopping smoking, controlling blood pressure, and controlling obesity, may all be quite important. Your doctor may recommend avoiding certain medications that carry a risk for blood clots, for example, birth control pills containing estrogens.

Many experienced doctors in the field recommend low-dose aspirin (81 or 100 mg per day) for people with positive tests, but who have not had a blood clot. This assumes that the person is not allergic to aspirin and has no medical reasons not to take it. Aspirin probably reduces the risk of clotting significantly (but not entirely). Prospective studies to determine if and how helpful aspirin is are underway. In patients with lupus, a medication called hydroxychloroquine (Plaquenil) is sometimes used in this situation. Hydroxychloroquine is very helpful in controlling skin and joint manifestations of lupus and several investigators have observed that it also reduces the risk of blood clots in lupus patients with antiphospholipid antibodies. [Back to top.](#) - 06/27/06 ~ R.A.S.R, MD

44. How long should you take baby aspirin and LMWH during your pregnancy? How long do should you take it after you have had the baby and why? (R.A.S.R, MD)

Most experienced physicians in the field recommend starting treatment as soon as the woman determines she is pregnant. Treatment is held around the time of delivery to avoid excess bleeding and then resumed for approximately six weeks. Treatment is continued because the period of time immediately following the birth of a baby, i.e., the postpartum period, is a time of increased risk for blood clots. [Back to top.](#) - 06/27/06 ~ R.A.S.R, MD

45. I've been diagnosed with APS. What are your thoughts on nutrition and exercise to help with this condition? (S.P.B, MD)

There are no specific diet or exercise guidelines for the APS patient. If you have APS, you're at heightened risk for problems involving the heart, lungs, and circulatory system. That means you should follow lifestyle guidelines calculated to minimize risk to those parts of your body, and they are essentially the very same guidelines that have been widely publicized for people who are known to suffer from high blood pressure, high cholesterol, and familial tendencies to overweight and/or diabetes.

To wit: Don't smoke. Avoid heavily sugared and heavily salted foods, and foods containing (or prepared with) saturated fats and transfats. Eat a generally well-balanced diet, being sure it includes fruits, vegetables, and fish (if you're a vegetarian, talk to your doctor about supplementary omega-3--and while you're at it, ask your doctor's advice about a multivitamin supplement). Keep your weight within the range your doctor says is right for you. Engage in moderate but regular exercise (needn't be a formal program; do whatever you enjoy, but DO it), which is good for weight control, keeping bones strong, and circulation generally. [Back to top.](#) - 07/20/06 ~ S.P.B, MD

46. I'm ten and one-half weeks pregnant, and have had two prior miscarriages. I've had three separate tests showing elevated anticardiolipin IgM (the values were 11, 14, and 18), and my hematologist says that I have APS. But a perinatologist with whom I've just met says that the positive ACL IgM tests are not indicative of APS at all, and that only ACL IgG is related to APS. Now, I'm quite confused! Do I have APS, or not? (S.P.B, MD)

Of course no physician can or should undertake a diagnosis without personally seeing the patient, and this young woman's specific question can't be answered here. Speaking generally, however: IgM and IgG are two of three subclasses of immunoglobulins--substances, produced by certain of the white blood cells, that contain specific antibodies; the third is IgA. The last is very rarely associated with APS, but the dismissal of one of the others isn't quite correct. While the IgG connection is more common, either IgG or IgM, or both, may be associated with APS, and the combination of the elevated ACL (although the values are not alarmingly high) and the two miscarriages certainly suggests the condition. If there were no contraindications, I would probably suggest that such a patient be on a daily regimen of "baby" (81 mg) aspirin, if she isn't already. [Back to top.](#) - 07/20/06 ~ S.P.B, MD

47. I have been struggling with a number of symptoms for almost three months now. It started with a horrible marbled rash on my feet and ankles, with numbness and pins and needles in my arms and legs. I've also had mental fog and some other symptoms. Livedo reticularis has been diagnosed in my feet, I've had a positive ANA test, and I have these antibodies. Does this necessarily mean that I have APS? (T.L.O, MD)

Technically speaking, the SYNDROME means that the patient has either had a blood clot (PE, DVT, stroke, etc) or recurrent miscarriages, in addition to the antibodies. Livedo reticularis, fatigue, aches & pains, memory

problems, etc, are frequently seen in patients with the syndrome, but they don't qualify for making a patient have the syndrome in the absence of clots or miscarriages. [Back to top.](#) - 07/27/06 ~ T.L.O, MD

48. What causes Antiphospholipid Antibody Syndrome? (S.P.B, MD)

With some other kinds of medical conditions, causes--and, thus, issues of cure and prevention--are reasonably clear. In the case of specific infections--influenza or TB, for example--once the causative agent (a virus or bacterium, for example) is found and its behavior in the body studied and understood, the challenges are to find the appropriate antibiotic or other drug to combat it, then to develop a vaccine to prevent future attacks.

In other kinds of illness, these issues are a great deal more complicated--and often very unclear. They are especially so in the case of the autoimmune diseases. The antiphospholipid syndrome (APS) is one of those, along with lupus, rheumatoid arthritis, diabetes, and a host of others.

We do know, in a very general way, what goes wrong: The body's immune system, normally a helpful--indeed, essential--operation that protects and defends the body against infectious agents and other invaders, misbehaves and attacks parts of the body itself. Elements of that defense system called antibodies, normally the front-line troops against "foreign" agents, instead go after the body's own tissues. In the case of diabetes, for example, the insulin-producing cells of the pancreas are targeted. In APS, the victims are substances, called phospholipids, that are integral parts of the membranes of cells. The cells that appear to be singled out for attack in APS are those of the circulatory system, and the syndrome is mainly manifested by problems with that system.

Why does this happen? We don't yet understand that. We believe that in APS, as in the other autoimmune disorders, heredity may be somehow involved--to a degree. If so, it doesn't involve a distinct pattern of inheritance as with, say, hemophilia, or Huntington's disease, in which we can predict, with mathematical confidence, the "odds" of relaying the condition. There's no such pattern in any of the autoimmune diseases--only the observation that relatives of patients often have autoimmune diseases too, or at least detectable antibodies. If there is some kind of hereditary mechanism that makes some people especially susceptible, or vulnerable--we don't yet know what it is.

But what sets off the active disease? Is the immune system activated against a particular threat, such as an infection, and then fails to "deactivate" after the threat has been dealt with? Perhaps. (Note pertinent to APS: Phospholipids aren't peculiar to humans; bacteria also contain them.) Does some element in the individual's environment trigger the process? Some toxic substance in the air? Maybe. Does something go amiss with the system's ability to distinguish between self and non-self ("foreign" substances)? That's possible, too.

We just don't yet know. All of these theories have been, and are being, examined, chiefly by looking into the history of patients with the particular condition and attempting to correlate the existence of certain syndromes with exposure to the suspected trigger. In APS, for instance, some researchers have suspected connections with certain viruses, but the results haven't been consistent; while one researcher finds that many of a group of APS patients has been exposed to a particular virus, another, studying a different group, finds no such connection. The search continues.

The short answer to the question of what causes APS is, for now, simply: We don't know. [Back to top.](#) - 10/06/06 ~ S.P.B, MD

49. I have APS, and I am wondering what my birth control options are. I realize that I can't take anything with estrogen--but what about the Mirena IUD and Micronor? Are those safe, since they are progesterone only? What other options can you recommend? (S.P.B, MD)

You're wise to be concerned about the kind of birth control you choose, and you're right in concluding that you shouldn't use either oral contraceptives or devices containing estrogen.

A word, first, about the specific products you mention, for those reading this who are unfamiliar with them. The Mirena is an IUD, which stands for "intrauterine device," a device placed within the uterus; this particular IUD releases a hormone called levonorgestrel over a five-year period.

Micronor is a so-called "minipill," a form of oral contraceptive; it contains a similar hormone, norethindrone. Both levonorgestrel and norethindrone are forms of progestin, a synthetic progesterone (a hormone, in addition to estrogen, produced in the ovaries; it's also produced by the placenta during pregnancy).

Expert opinions, frankly, differ among both rheumatologists and gynecologists when it comes to the progestin-only products. There's general agreement that IUDs all pose some risk of uterine perforation or other injury, and the particular one you mention is specifically not recommended for women who have had any prior pelvic inflammatory disease (PID), have experienced an ectopic (outside the womb) pregnancy, or who have not successfully borne at least one child. "Minipills" are generally viewed as not entirely dependable and have been reported to cause irregular bleeding.

My own feeling is that in the presence of a systemic illness that has itself been associated with a variety of other problems, it's best to avoid all hormonal forms of pregnancy prevention. In my view, your best choice is a physical barrier form of contraception, of which there are a number of choices: condom, diaphragm, cervical cap, and so on.

An alternative, if you are in a lasting relationship and are sure that you want to completely avoid the chance of pregnancy, is surgical contraception--tubal ligation ("tube tying"), or, for the man, vasectomy.

Although these procedures have occasionally been reversed, they should be considered permanent. [Back to top.](#)
- 10/29/06 ~ S.P.B, MD

50. **Will having APS shorten my life? Will I be in any way impaired? Are there changes I should make in my life because I have APS? (S.P.B, MD)**

The answer to your first two questions is: Not necessarily. That may, in turn, depend upon you--bringing us to your third question. In my opinion, the answer is definitely yes.

Historically and statistically, APS is associated with higher-than-usual susceptibility to a number of conditions with life-shortening potential.

Thus, while everyone should take prudent precautions to preserve and optimize health, APS underscores the importance of these precautions.

As you doubtless know, the chief potential threat in APS is the formation of clots that can interfere with the normal function of your heart and circulation (thus threatening other organs depending on that circulation, as well). That is, APS poses what medicine calls a "risk factor." The risk is heightened if it's combined with OTHER risk factors. You can take a number of steps to eliminate some of those factors:

- ◆ Two obvious and very serious risks are smoking and obesity. If you smoke, quit. If you're overweight, get your weight down to normal and maintain it.
- ◆ Eat a sensible, balanced diet that's low in cholesterol and other fats (including trans fats), and includes such natural anticoagulants as peas, onions, scallions, and garlic.
- ◆ If you've already been diagnosed with any heart or circulatory problem--high blood pressure or high lipids, for example--and your doctor has prescribed medications and/or other measures, follow those directions faithfully.
- ◆ Don't take oral contraceptives, which are thrombophilic--i.e., tending to encourage clot formation. (And since APS is not uncommonly seen in families, urge close relatives who may contemplate going on "The Pill" to be tested for APS first.)
- ◆ Talk to your physician about taking daily 81 mg ("baby" or "low dose") aspirin, which discourages clot formation. NOTE: While this is an over-the-counter drug, you shouldn't put yourself on such a regimen without medical advice.
- ◆ Other tests, for conditions that might suggest additional precautions, might be helpful, and your doctor may have already routinely performed such tests. These might include screening for lupus, for instance, which is often associated with APS, and for certain factors that may signal higher-than-average risk of heart disease.

◆ If you contemplate pregnancy, be sure to discuss it with your regular physician, and also be sure that you have expert prenatal care and monitoring by an obstetrician familiar with APS and skilled in the management of high-risk pregnancies. (And don't even THINK about home birth; charming as the idea may seem, it's not for you.) [Back to top.](#) - 12/24/06 ~ S.P.B, MD



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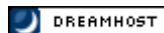


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