**Patient Questions (with answers) & Stories (Challenges, Concerns, Uplifitng and Success Stories) Received During Our 2018 World Thrombosis Day Support Campaign.**

**Patient Question 1**:
I am 34 years old. I got my first blood clot when I was 18 while taking the birth control pill. Over the next 6 years or so, I was pregnant four times, two resulted in preterm induction and delivery at around 22 weeks due to Class I HELLP syndrome, and two resulted in miscarriages. After my first pregnancy loss I was diagnosed with APS, subsequent pregnancies were treated with heparin injections, but were obviously still unsuccessful. I have been taking warfarin daily to prevent additional blood clots since then. My INR is overseen by my PCP, I do not currently see a rheumatologist or hematologist. Based on doctor's recommendations I have not tried to get pregnant again. I exercise regularly and eat a balanced diet, don't smoke or drink, and maintain a healthy BMI. My question is regarding the safety and immune response to elective surgery. I am looking into having a breast lift and augmentation done, I just wondered if there was any research or medical recommendation about people with APS having this type of surgery?

**Answer 1:**
Surgery is a major risk factor for the formation of thrombosis (blood clots) in everyone, due to surgical damage to tissue and blood vessels and immobilization during and after surgery. Antiphospholipid antibody-positive patients are at higher risk for thrombosis compared to the general population. Thus, the risk and benefits of surgical procedures, especially the ones that may not be essential, should be discussed with your physicians. In general, it is very important to minimize the time spent off blood-thinning medications, so warfarin and/or heparin should be restarted as soon as it is safe to do so after surgery. For more information, you can visit https://www.hss.edu/conditions_top-ten-antiphospholipid-antibody-positive-patients-should-know-pre-surgery.asp

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**Patient Question 2**:
Can & should APS patients get the flu shot and other vaccinations?

**Answer 2:**
Antiphospholipid syndrome patients can receive flu shots. Regarding “other” vaccinations, generally there is no problem; however patients (with/without other systemic autoimmune diseases) receiving immunosuppressive medications should discuss with their physicians before any vaccination.

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**Patient Question 3**:
Is there any indication that following specific diets (e.g., paleo, auto-immune protocol, vegan, eliminating sugar/processed foods, etc.) may help minimize symptoms or help in any way individuals with APS?

**Answer 3:**
The only specific diet recommendation is a "healthy diet" to improve or prevent cardiovascular disease risk factors such as hypertension (high blood pressure) or hyperlipidemia (raised cholesterol). In addition, warfarin-receiving APS patients should avoid large amounts of vitamin K rich foods, such as kale, spinach, broccoli and also green tea, which can lessen warfarin's effectiveness. Small amounts of vitamin K rich foods should not cause a problem and you should try to maintain a consistent amount of vitamin K in your diet. Cranberry juice and alcohol can increase the effect of warfarin, potentially leading to bleeding problems and so these should be avoided or consumed in small amounts while on warfarin.

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**Patient Question 4**:
Are there any supplements / vitamins that individuals with APS may want to consider such as Vitamin D, Vitamin C, B100, DHEA – any others?

**Answer 4:**
There are small studies suggesting that vitamin D deficiency increases the risk of blood clots in antiphospholipid antibody positive patients. Independent of these studies, vitamin D deficiency and insufficiency should be corrected in all aPL-positive patients based on the general population guidelines.

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**Patient Question 5**:
Are there any vitamins / supplements that individuals with APS should NOT take?

**Answer 5:**
Please see Answer #4. Warfarin-receiving APS patients should follow the specific diet instructions detailed above and discuss all the vitamins/supplements with their doctors prior to starting these, as some may interact with the anticoagulant effects of warfarin.

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**Patient Question 6:**
Are there any foods to be avoided by an individual with APS (assuming only taking aspirin)?

**Answer 6:**
Please see Answer #3.

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**Patient Question 7**:
Is taking Melatonin acceptable for someone with APS (assuming only taking aspirin)?

**Answer 7:**
Yes, taking melatonin is acceptable.

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**Patient Question 8:**
Can you take steroids with APS and on anticoagulants? I am hearing conflicting information.

**Answer 8:**
Yes you can take steroids and anticoagulants. Given that sometimes steroids can interact with warfarin, close international normalized ratio (INR) monitoring, especially after starting steroids, is recommended. Steroids may cause gastritis (inflammation of the stomach) and so if an individual has a history of heartburn/indigestion or stomach ulcers, then it is generally a good idea to prescribe a drug, such as a proton pump inhibitor (PPI), to counteract this when steroids are given together with warfarin.

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**Patient Question 9**:
Are statins helpful for APS?

**Answer 9**:
Statins are a class of medications typically used to lower cholesterol levels. However, these medications also have anti-inflammatory effects on various cells in the body. Mouse studies suggest that statins can decrease clot size through interactions with the clotting cascade. In APS patients, statins decrease the level of proteins involved in inflammation and blood clots; however there are no studies demonstrating that statins decrease the risk of blood clots in antiphospholipid antibody positive patients. Thus, currently, there is no definitive evidence that statins prevent clots in APS patients and clinical studies are needed. Despite the lack of strong clinical data, statins are rarely used in difficult-to-treat APS patients. Like warfarin, this class of medications should be avoided in pregnant patients as they can cause birth defects.

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**Patient Question 10:**
Does Hydroxychloroquine (Plaquenil®) help APS?

**Answer 10:**
Hydroxychloroquine is an antimalarial medication, which is used to treat systemic lupus erythematosus (SLE, also known as lupus). Hydroxychloroquine has anti-inflammatory effects and also inhibits platelet clumping, which is a key step in blood clot formation. There is evidence to suggest this drug may help reduce the blood clotting effects of aPL

in mice and also decrease the risk of blood clots in SLE patients. In order to understand the protective role of hydroxychloroquine in antiphospholipid antibody (aPL) positive patients without other systemic autoimmune diseases (for instance, lupus) controlled studies are planned or undergoing. For the time being, hydroxychloroquine may be used as an adjunctive therapy (supportive treatment used together with the primary treatment) in APS patients with difficult-to-control aPL-related clinical problems.

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**Patient Question 11:**
I am a female aged 45. I was diagnosed with APS two years ago after years of me going back and forth to my GP telling them I knew there was something not right. I was constantly exhausted and had memory blanks. My arthralgia and arthritis was also worsening. I had been diagnosed with Reynaud's approximately ten years previously. I had a suspected (but unproven TIA) roughly three years ago as well as bad bout of glandular fever. I have headaches (since the age of 15) on a daily basis and migraines about once or twice a month, which I am on pain management medication for. I have asthma (since the age of 15) which has been getting worse lately. Last year I also developed meralgia paraesthetica in my right thigh which has been causing me great pain and discomfort and pain if I stand up unmoving for more than half hour or walk on it for more than two hours. I have, what I feel are extreme hot flashes (even when static) but have been told I am not going through the menopause (I have had a partial hysterectomy).

I have never been referred to an APS specialist and have not seen nor heard from my rheumatologist for a year (even then it was at my request). I have not seen a pain management specialist for over ten years. I do question whether I should have regular follow up visits, but also whether I should be referred to an APS specialist? Also should I be doing more to monitor my condition?

**Answer 11:**
Many people can have antiphospholipid antibodies (aPL) in their blood without developing blood clots or other aPL-related clinical problems. Furthermore, Not every positive aPL test is clinically relevant, and not every aPL-positive patient has the same risk of aPL-related clinical problems. You should discuss with your physicians if you have a "clinically significant aPL profile", and if so, you should be referred to an APS specialist. Some of the features of "clinically significant aPL profile" are:

- Antiphospholipid antibodies should be positive in tests conducted on two occasions at least 12 weeks apart.
- The lupus anticoagulant (LA) test is the most important aPL test.
- Anticardiolipin antibody (aCL) and aβ2GPI have several subclasses; immunoglobulin (Ig) subclass IgG and IgM levels greater than or equal to 40 units (40U) are clinically more significant than lower levels.

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**Patient Story 1:**
I would like to let you know that when I was diagnosed with APS in 2011, I did not have a blood clot, the way we discovered that I have APS was by a mistake I made when I went for a blood test.

I have been sick my whole life, doctors couldn't find what was wrong. At the age of 11 was diagnosed with Porphyria. Kept away from most medications, Sun, red meat and green vegetables. I actually get sick when I do eat red meat and green vegetables.

I struggled 5 years to get pregnant, then I was blessed with a son at the age of 25. Then my health really took a knock. After my 8th miscarriage I had a hysterectomy at The age of 31. The doctor wrote on the note Hugh Syndrome? No one took notice. I kept getting migraines and feeling sick.

At the age of 36 I was playing around with a stapler and the one guy pressed the staple in my arm, when I removed the staple the only blood that came out was like jelly. We still joke about that because I don't bleed. It literally takes hours. But then I also really got worse. No one could touch me because my skin hurt when someone touched it, I would get seizures and lost consciousness for hours. I went to the doctor and they tested for Lupus. Test was false/positive and that I have fibromyalgia. As a second opinion I did private blood tests. I asked the nurse who did the rest, If they can test for Fibromyalgia and she said yes. Showing on the form Fibro. Results - positive for APS. Lupus - LA present (Whatever that means). I have never heard about APS ,and my Porphyria test was now negative. Back to the doctor. Since I go to a state hospital. You don't always see the same one. This doctor, sitting with the results in her hand tells me that it is all in my head and that I should go and see a psychiatrist. I did, results - no treatment, still getting seizures. Had to stop working cause I would get seizures and the staff didn't know how to handle it. The one day I decided to go for a walk and all of a sudden I forgot where I was or how to get home, and my body freezed up. They took me to a private doctor. I told her about the blood tests. She draw blood, she mentioned how thick the blood was, she gave me an injection for the muscles and I ended up in ER. Those blood test came back - Positive High for APS. Back to the doctor in the hospital. She says that APS is a syndrome, which means that you must have 2 positive blood tests, at least 3 miscarriages and a blood clot. So since I have not had the blood clot. I don't have APS. (So why do I feel sick, why do I get seizures)

I ended up in Hospital again but this time I had 7 seizures in an hour. According to my sister, At one stage I mumbled to her that it feels like a hot iron is being pressed into my right eye. After that I was confused and lost the feeling in my left side. They did not do any scans, they gave me cholesterol pils and that's it. After a week in hospital. I went home. By now I had 3 positive test results for APS. But still they said that I don't have APS.

3 years later 4th test positive + CT scan shows a minor stroke.

7 years later. I still don't get treatment (Doctors still says it's not APS). I have changed my diet, I supplement with Glyconutrional Supplements. And I still have my good days and really bad days. But hopefully my story can make a change on how doctors look at APS. I think not everyone has the same symptoms, have all the criteria for APS. Maybe the doctors in South Africa should learn more about APS.

**Comment 1:**
Thank you very much for sharing your story.

**Final Note:**

We want to thank everybody who has contributed to our 2018 World Thrombosis Day Support Campaign.

APS ACTION
APS Foundation of America
APS Foundation of Australia
APS Support Group UK

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