APS Foundation of America

ANTIPHOSPHO...WHAT?

APS Foundation of America, Inc.

The APS Foundation of America Board of Directors would like to wish all of our volunteers, donors, friends, forum participants & those individuals who have contributed to the success of this Foundation. We would not have made it 20 years with out you!

Happy 20th Birthday APSFA!!

The Present and Future of APS Research June 2025

UNIVERSITY OF MICHIGAN MEDICAL SCHOOL
MICHIGAN MEDICINE

Welcome to APS Awareness Month! What has happened in APS research over the past 12 months? And where is the field headed next? We surveyed APS researchers at the University of Michigan, asking them to highlight something they have been thinking about over the past year.

Ramadan Ali, PhD (faculty member): I remain interested in the potential therapeutic benefits of plant-derived natural compounds in the context of thrombo-inflammatory diseases like APS. Several years ago, my work demonstrated the protective effects of ginger-derived compounds in models of lupus and APS. We went on to validate the anti-inflammatory benefits of a whole ginger extract in healthy individuals and have worked hard over the past year (albeit unsuccessfully, so far) to secure the funding needed to now bring this concept to patients with APS.

Jason Knight, MD, PhD (faculty member): In collaboration with graduate student Thalia Newman, I recently summarized my thoughts on the current state of the field and some important future directions. The article was just published in Arthritis & Rheumatology, the flagship journal of the American College of Rheumatology. I am especially excited by the momentum I see building for innovative clinical trials that hope to treat APS closer to its source. I think patients living with a diagnosis of APS will be excited by what they see over the next couple of years.

Chao Liu, PhD (postdoctoral fellow): I have experience studying web-like structures called neutrophil extracellular traps (NETs), which harm blood vessels in various inflammatory diseases. For example, in a recent paper, I found that inhibiting NETs might be a way to protect the blood vessels of diabetic patients. I recently started working on an APS project that will investigate whether blocking the inflammatory pathway known as the complement system may protect against NET formation and downstream thrombosis in APS. This is an example of trying to treat APS closer to its inflammatory source.

Jacqueline Madison, MD (faculty member): Over the past year, I have been working to expand the clinical trials available to patients with APS, most notably through the DARE-APS multi-center trial of daratumumab. Daratumumab is a drug we are attempting to repurpose from the treatment of certain blood cancers. Along with an excellent fellow in pediatric hematology, Kevin Lewis, I also recently summarized the current state of pediatric APS research and clinical care for practicing rheumatologists.

Bruna de Moraes Mazetto Fonseca, PhD (postdoctoral researcher): Since joining the team a few years back, I've been exploring two critical aspects of APS: pregnancy loss and platelet hyperreactivity. To date, we have found that white blood cells called neutrophils impair placental cell function, leading to pregnancy loss in mouse models of APS. This hints that we may eventually be able to repurpose anti-neutrophil drugs to improve the outcomes of APS pregnancies. In a separate project, I have found that a special membrane channel called PANX1 appears to be crucial for platelet activation in APS. Targeting PANX1 will likely require new drug development, but we are up for the challenge if we can secure additional funding.

Somanathapura NaveenKumar, PhD (faculty member): I've had the opportunity to work on several exciting APS projects over the past year or so, including a study that demonstrated how a unique inflammatory protein called calprotectin interacts with platelets in APS. Another focus of my work has been enzymes called ectonucleotidases, which regulate extracellular chemicals that control platelet-driven inflammation and clotting. My research has found that some patients with APS exhibit reduced ectonucleotidase activity and increased neutrophil-platelet aggregates, indicating a defect in the regulation of inflammation (Continued on pg 10)

Click Below to Follow APSFA

SHARE

Patient Stories & Articles Needed!

We are in need of patient stories to feature in our newsletters. Every APS patient has a story to tell and yours could be shared with the entire APS community.

We also need related articles such as book reviews, poems, recipes, interest articles, quotes, etc.

If you are interested in sending us your story, please write to articles@apsfa.org and we will send you our guidelines.

Without your help our newsletter cannot be a success!

Inside this issue:

Letter from the President

Awareness month is here and it is time to get busy spreading awareness about APS. So, I am calling all hands on deck!

We have been busy networking with other organizations like CARRA, Autoimmune Association, ITSH, World Thrombosis Day, ICAPA, Defense Health Research Consortium, Global Jeans and the Arthritis Foundation to name a few. We have been working with coalition groups to get more research for autoimmune disease in general, medication coverage and more awareness for maternal death and loss for example. We are also networking with corporations who can help fund professional videos, CME/CE creation, and distribution.

Sadly, federal rare disease funding has come to a halt so it has left many project hurting. Many hospitals are reaching out to for financial aid to finish their APS projects and we just do not have the funding to help them at this time.

*We are still looking for someone to create a new info video for our website, if anyone would like to make a **professional** one, please drop us a line at apsfa@apsfa.org If we do not have someone I will pay AI to create it.*

*To get this newsletter back on track, **we are in need of patient stories** to feature in our newsletters. Every APS patient has a story to tell and yours could be shared with the entire APS community. We also need related articles such as book reviews, poems, interest articles, quotes, etc. If you are interested in sending us your story, please write to articles@apsfa.org and we will send you our guidelines. Without your help our newsletter cannot be a success!*

As a reminder are on Walmart's SparkGood. You can donate money to the APSFA just by shopping. Just set the APSFA to your designated charity. We are also with Target and Front Door.

*We encourage you to follow us on Facebook and Instagram to get the **latest** APS news. While Twitter has a great exchange with medical professionals interested in APS we do not have a following there anymore and are considering deleting the account.*

That is about all the news I have to report. Once again, I hope this newsletter finds you in the best of health and with a perfect INR level.

Sincerely,

Tina Pohlman

President & Co-Founder

APSFA Board of Directors

PRESIDENT, CO-FOUNDER, EXECUTIVE DIRECTOR
Tina Pohlman, WI

VICE PRESIDENT
Karyn Lombana, FL

SECRETARY
Kim Nault, CA

DIRECTOR
Tammy Wood, WI

CO-FOUNDERS
Todd & Heidi Ponagai, MI

MEDICAL ADVISORS

Dourk Erkan, MD, MPH
Associate Attending Rheumatologist, Hospital for Special Surgery
Associate Physician-Scientist at the Barbara Volcker Center for Women and Rheumatic Diseases
Associate Professor of Medicine at Weill Cornell Medical College

Jason Knight, MD
Rheumatologist
University of Michigan

Thomas L. Ortel, MD, PhD
Director Duke Clinical Coagulation and Platelet Immunology Laboratories
Director Anticoagulation Management Service

Barry Myones, MD
Pediatric Rheumatologist

Christopher Repetesky, MD
Division of Rheumatology & Immunology
University of North Carolina at Chapel Hill

Robert Roubey, MD
Division of Rheumatology & Immunology
University of North Carolina at Chapel Hill

Donate to the APSFA Today!

June is APS Awareness Month

Every June, we recognize APS Awareness Month — a time to shed light on Antiphospholipid Syndrome (APS), a serious and often misunderstood autoimmune disorder that affects thousands of lives around the world.

Despite its life-threatening potential, APS remains underdiagnosed, underresearched, and widely unknown, even among medical professionals. That's why awareness is not just important — it's urgent.

What Is Antiphospholipid Syndrome (APS)?

APS is an autoimmune disorder in which the body mistakenly produces antibodies that increase the risk of blood clots. These clots can form in veins or arteries, causing:

- Deep vein thrombosis (DVT)
- Stroke
- Pulmonary embolism (PE)
- Heart attacks
- Pregnancy complications, including miscarriage, stillbirth, and preterm delivery
- Organ damage (lungs, kidneys, brain, skin)

APS can affect both adults and children, and it often overlaps with other autoimmune conditions like lupus, Sjögren's syndrome, and Hashimoto's thyroiditis.

Pediatric APS: A Growing Concern

While APS is more commonly diagnosed in adults, children and teens can also be affected. Pediatric APS is rare but real — and often more challenging to detect due to vague or overlapping symptoms.

There is no standardized treatment protocol for children, making research and awareness even more critical to improve outcomes and prevent long-term complications.

Why Awareness Matters

Most people have never heard of APS until it affects them or a loved one — and by then, serious damage may have already occurred.

Lack of awareness leads to:

- Delayed diagnosis
- Missed warning signs
- Limited access to specialists and treatment options

Early diagnosis can save lives. Awareness can empower people to ask the right questions and seek help when symptoms are brushed aside.

How You Can Help During APS Awareness Month

This June, we invite you to take action. Here's how:

Educate

- Share APS facts on social media
- Distribute flyers, posters, and infographics
- Talk openly about the condition and its risks

Donate

- Support the APS Foundation of America at apsfa.org/donate
- Donate $25 or more via PayPal in June and receive a limited-edition 3-inch awareness sticker.

Advocate

- Encourage your local representatives to support rare disease funding
- Ask local clinics to include APS in educational materials

Support

Don your burgundy gear, ribbons, and accessories to spark conversations and show solidarity.

Every Voice Counts

APS may be rare, but its impact is profound. By participating in APS Awareness Month, you're helping to illuminate a condition that has lived in the shadows for too long.

Together, we can change the story — with more research, earlier diagnoses, and stronger support for patients and families.

Join us this June. Speak up. Spread awareness. Save lives.

Introducing In-Home Care When Your Loved One Says 'No'
By Family Caregiver Alliance

Desperate though caregivers may be for a temporary respite from their care responsibilities, many care recipients are resistant to strangers coming into their home to help. The help may be perceived as an invasion of privacy, a loss of independence, or a waste of money. Yet in-home assistance is often critical in offering caregivers a break and time to relax and rejuvenate. There are ways to make this transition easier. Here are some tips for making your loved one feel more comfortable with in-home help:

Start gradually. Begin by having the aide come only a few hours each week, then add hours as your loved one builds a relationship with the helper. If you feel comfortable with the attendant running errands or preparing meals that can be brought to the house, you can start with those services, which can be done outside the home.

Listen to your loved one's fears and reasons for not wanting in-home care. Express your understanding of those feelings. If possible, get your loved one involved in choosing the aide. He or she will feel more invested and comfortable with the decision.

"This is for me. I know you don't need help." Expressing the need as yours, rather than your loved one's, helps maintain her dignity and independence. You can also add that having someone stay at home allows you not to worry while you are gone. Make it clear that you will be coming back.

"This is prescribed by the doctor." Doctors are often seen as authority figures, and your loved one may be more willing to accept help if she feels that she is required to do so.

"I need someone to help clean." Even if this is not the real reason, people often allow someone in to clean when they "don't need" care for themselves.

"This is a free service." This strategy may work if other family members are paying for the home care or if it is provided without charge. Your loved one may be more open to using the service since she does not feel that she is spending money for it.

"This is my friend." By pretending that the attendant is your friend, you are relating the home care worker to the family. This can help establish trust and rapport. You can also say that your "friend" is the one who needs company and that by having him or her over your loved one is helping him out.

"This is only temporary." This strategy depends on the condition of your loved one's memory. If she often forgets what you say, then she may also forget that you said this. By presenting the situation as short-term, you will give your loved one some time to form a relationship or become comfortable with home care as part of her daily routine, and give you a chance for a well-deserved break.

Tips For Trying New Activities

As your care recipient's dementia (or any cognitive decline/ deficit) progresses, some activities will become harder to perform cognitively or physically. These may be the signs that they need a new activity. Use the following tips to help find new activities for your care recipient to try: Introduce the new activity slowly into their routine. They may be resistant to trying something new at first, but this doesn't always mean they won't like it later! Don't be afraid to experiment and make adjustments as you go. Where possible, let them pick a new activity.

Pay attention to their behaviors and emotions. Are they excited, bored, frustrated, or sad? What is it about the activity that causes them to feel this way? Incorporate new activities with similar qualities to what they enjoy and avoid boring or upsetting ones. To see if they are interested, ask: "Did you enjoy this activity? Would you like to try this again sometime?"

Brainstorm past jobs or hobbies. If they worked as accountants, they might like to sort coins or type on a calculator. If they love shopping for clothes, open their closet and let them take out clothing they enjoy and put it in a basket. Consider their activity level. Are they restless or like to pace or rummage through things? Is it difficult to encourage them to participate? You may need to adjust your approach and expectations of what it means to participate in an activity.

Match activities to their abilities. Choose activities to emphasize your care recipient's strengths. Consider what they CAN do and choose an activity matching those skills. If they are still having trouble, try to make the activity easier.

Be patient and flexible. Skills and abilities change over time.

Some days will be easier and more challenging than others. It's important to be patient with your care recipient and with yourself.

You both are doing your best.

EXPERT TIP: Try an activity on at least three different occasions before deciding your care recipient isn't interested in it.

Top 10 Points Patients Should Know About Classification and Diagnosis of APS

By Mert Sevgi, MD; Yasaman Ahmadzadeh, MD; Stephane Zuily, MD, PhD; Medha Barbhaiya, MD, MPH; Doruk Erkan, MD, MPH

What is the definition of antiphospholipid syndrome?

Antiphospholipid syndrome (APS) is an autoimmune disorder typically characterized by blood clots and pregnancy complications. However, the spectrum of APS-related clinical symptoms is much broader (see below). APS can develop alone or in association with other autoimmune conditions such as lupus. (Learn more about antiphospholipid syndrome terminology.)

Table showing different organ systems and how APS may affect them

Organ System	Selected Antiphospholipid Syndrome-related Clinical Problems
Nervous system	Stroke, transient ischemic attacks1, memory problems
Kidney	High blood pressure, chronic kidney disease, protein in the urine
Heart	Myocardial infarctions, vegetations2 on valves, thickened and leaky valves
Blood	Anemia, low platelet counts
Skin	Livedo3, skin ulcerations
Blood vessels	Deep venous thrombosis4 (DVT)
Lungs	Pulmonary embolism5, pulmonary hypertension6
Pregnancy	Miscarriages, premature births, fetal growth restriction

1. Episodes of neurological problems such as speech, movement or behavior abnormalities that typically last less than an hour and resolve on their own. Their mechanism of development is similar to a stroke. It is due to blockages in blood vessels that supply the brain, but there is no permanent damage to the brain.
2. Debris of coagulated tissue that sits on heart valves which develop due to damage caused by antibodies to valves.
3. Reddish-purple discoloration of the skin in a lace-like pattern, associated with the damage to small blood vessels.
4. Blockage of veins, usually in the leg, by a blood clot due to damaged inner lining of veins and propensity to clotting. It can present with swelling, redness and pain in the leg.
5. Blockage of blood vessels within the lung. This usually develops when part of the blood clot that was in the leg breaks off and travels to the lung. It can cause shortness of breath and chest pain.
6. Increased blood pressure within the main blood vessel that start from the heart and goes to the lungs. Usually develops due to persistent clots that travel from the legs to the lungs. It can cause strain on the heart as it tries to pump against increased pressures.

What are the differences between disease-specific classification criteria and diagnostic criteria?

Classification criteria are intended to be used in a medical research setting. Diagnostic criteria are used in a clinical setting for the purpose of managing diseases in patients. The two sets of criteria may have overlapping elements, but they have separate goals.

Classification criteria – Medical research setting

The goal of classification criteria is to ensure that patients with common characteristics, thought to be specific for a certain disease, are included in appropriate research studies. This helps ensure the integrity of the research data during the analysis of the study. Classification criteria do not necessarily encapsulate all of the clinical or laboratory features of that particular disease. Rather, the goal is to capture a uniform group of patients with a similar clinical presentation for medical research purposes only.

Diagnostic criteria – Clinical setting

The goal of diagnostic criteria is to identify, as accurately as possible, whether patients have that particular disease. While some of the diagnostic criteria may overlap with the classification criteria, many of the uncommon signs and symptoms of a disease are not included in the classification criteria. However, this does not mean they are not a feature of that disease. Diagnostic criteria aim to maximize the number of patients that can be identified as having a particular disease. This is in contrast to classification criteria, which are more stringent in order to identify a more specific cohort of patients.

Are there classification criteria for antiphospholipid syndrome?

Yes, the revised Sapporo APS Classification Criteria have been used for classifying APS patients. Published in 1999 and updated in 2006, these criteria allowed researchers to determine who can be identified as an APS patient to participate in laboratory or clinical research. A simplified version of the APS classification criteria is shown below. Based on these classification criteria, patients who have at least one positive clinical and one positive laboratory criteria are considered to have a diagnosis of APS suitable for research purposes.

Revised Sapporo Antiphospholipid Syndrome Classification Criteria (simplified)

Clinical criteria

Blood clots within arteries, veins, or small blood vessels.

Adverse outcomes during pregnancies, such as three or more spontaneous abortions before 10th week of pregnancy, unexplained fetal deaths1 at or beyond 10th week of pregnancy, or premature births before 34th week of pregnancy due to severe preeclampsia2 or eclampsia3.

Laboratory criteria (antiphospholipid antibody tests)

Positive lupus anticoagulant test.

Top 10 Points Patients Should Know About Classification and Diagnosis of APS—Continued

Positive anticardiolipin antibody (aCL) IgG or IgM.

Positive anti-Beta-2-glycoprotein-I antibody (aβ2GPI) IgG or IgM.

Spontaneous death of fetus due to any cause which leads to pregnancy loss.

A disorder characterized by new-onset high blood pressure that develops after the 20th week of pregnancy that leads to damage in various organs, most commonly protein leakage from kidneys. Severity depends on the degree of damage to organs or level of blood pressure.

Development of seizures in women with preeclampsia that cannot be explained by any other cause.

However, some of the limitations of the revised Sapporo APS Classification Criteria included:

No representation of some of the well-established clinical problems related to APS.

No clear definition on what aPL test level indicates "positive" aPL.

A lack of risk assessment based on the presence or absence of other risk factors.

Thus, an international group of APS clinicians and/or researchers, supported by American College of Rheumatology (ACR) and European Alliance of Associations of Rheumatology (EULAR) (co principal investigators Dr. Doruk Erkan [New York, NY] and Dr. Stephane Zuily [Nancy, France]), developed and recently published a more comprehensive classification criteria (also known as 2023 ACR/EULAR APS Classification Criteria).

What is new in 2023 ACR/EULAR antiphospholipid syndrome classification criteria?

New APS classification criteria are based on a weighted point system of symptoms, physical examination findings, and laboratory results. These are calculated across eight domains, divided into two types: (1) clinical domains and (2) laboratory domains. Please refer to the original publication or the classification criteria calculator for details.

The new classification criteria include an entry criterion followed by additive weighted criteria (score range 1 to 7 points each) clustered into six clinical and two laboratory domains. Patients accumulating at least three points each from the clinical and laboratory domains are classified as having APS for research purposes.

In summary, these new ACR/EULAR APS classification criteria were developed using rigorous methodology with multidisciplinary international input. Hierarchically clustered, weighted, and risk-stratified criteria reflect the current thinking about APS, providing high specificity and a strong foundation for future APS research.

Antiphospholipid Syndrome (APS)

Entry Criterion
≥ 1 documented clinical criterion + ≥ 1 positive aPL test

Clinical Domains	Points
VENOUS THROMBOEMBOLISM	
☐ With high VTE risk profile	1
☐ Without high VTE risk profile	3
ARTERIAL THROMBOSIS	
☐ With high CVD profile	2
☐ Without high CVD profile	4
MICROVASCULAR INVOLVEMENT*	
☐ Suspected	2
☐ Established	5
OBSTETRIC	
☐ Fetal death (≥16w <34w) without PEC/PI with severe features	1
☐ Severe PEC or severe PI (<34w)	3
☐ Severe PEC and severe PI (<34w)	4
CARDIAC VALVE	
☐ Thickening	2
☐ Vegetation	4
THROMBOCYTOPENIA (lowest 20-130G/L)	2

Laboratory Domains (aPL)	Points
LUPUS ANTICOAGULANT (LA) POSITIVITY	
☐ One time	1
☐ Persistent	5
ANTI-CARDIOLIPIN (aCL) / ANTI-BP2GP1 POSITIVITY**	
☐ IgM only: moderate-high for aCL and/or anti-B2GP1	1
☐ Presence of IgG	
☐ moderate positivity for aL and/or anti-B2GP1	4
☐ high positivity for aCL OR anti-B2GP1	5
☐ high positivity for aCL AND anti-B2GP1	7

Only count the highest weighted criterion within each domain

Do not count if there is an equally or more likely explanation than APS

*Microvascular involvement:

☐ Suspected: livedo racemosa, livedoid vasculopathy (without pathology), aPL nephropathy (no pathology available), pulmonary hemorrhage (symptoms or imaging)

☐ Established: livedoid vasculopathy (with pathology), aPL nephropathy (with pathology), pulmonary hemorrhage (BAL or pathology), Myocardial disease (imaging or pathology), Adrenal disease (imaging or pathology)

**aPL titers (by ELISA): moderate titer => 40-79U; high titer => ≥ 80U

Classify as APS if ≥ 3 points from clinical criteria AND ≥ 3 points from aPL domain

Adapted by @Lupusreference from #ACR22 session 135150 (Erkan et al.)

Are there diagnostic criteria for antiphospholipid syndrome?

There are no diagnostic criteria for APS.

If a patient has signs and symptoms that suggest they have APS, laboratory testing to determine the presence of antiphospholipid antibody (aPL) is ordered to establish the diagnosis. However, aPL test results need to be interpreted cautiously, because not every person who has a positive aPL test result necessarily has APS or clinically relevant aPL positivity.

Our bodies may develop aPL due to conditions other than APS, such as in responses to infections. Patients who have positive initial aPL tests, but test negatively in repeated confirmatory tests after a period of time are said to have "transient aPL positivity." In other words, the aPL positivity is temporary. If their aPL results remain positive, then patients are said to have persistent aPL positivity. Some people may also have aPL levels that are frequently slightly elevated (technically a positive result) but in such low levels that these results are not considered "clinically meaningful" – meaning they do not indicate that a person has APS.

To be considered clinically meaningful, an aPL test should:

- Adhere to the guidelines for testing methods and use validated tests.
- Remain persistently positive on two separate time points performed at least 12 weeks apart.
- Be determined based on LA test and/or moderate-to-high anticardiolipin antibody (aCL) or anti-Beta-2-glycoprotein-I (aβ2GPI) antibody positivity (of note, low titers of aCL or

Top 10 Points Patients Should Know About Classification and Diagnosis of APS—Continued

aβ2GPI are not clinically meaningful).

- Antiphospholipid syndrome is diagnosed by your physician based on the careful assessment of:

Clinically meaningful aPL profile, as discussed above.

- Clinically relevant health problems (that is, health problems known to frequently occur due to aPL).
- Additional thrombosis risk factors (for instance birth control pill use or smoking) or medical problems.

Why is diagnosing antiphospholipid syndrome challenging?

Antiphospholipid syndrome diagnosis can be challenging due to two problems: missed diagnosis and over-diagnosis.

Missed diagnosis – APS is not even considered in the list of possible diagnoses to explain a patient's medical problems.

Example clinical scenario: A patient goes to the emergency department complaining of leg swelling and redness. She is taking birth control pills for contraception and she is a smoker. This is her first time experiencing similar symptoms; however, she has a history of recurrent second trimester miscarriages as well as slightly low platelet counts. She is diagnosed with a blood clot in association with additional thrombosis risk factors and is treated appropriately. The patient does not undergo testing for aPL; and APS is not included in the differential diagnosis, possibly because she had other risk factors (birth control pill and smoking) that could explain her tendency to develop blood clots.

Overdiagnosis – APS is diagnosed incorrectly, based on a single, weak positive aPL test.

Example clinical scenario: The patient above undergoes testing for aPL; results are positive but her anticardiolipin antibody (aCL) IgG is only slightly elevated above normal antibody titers (low level aCL).

Is there any role for APS classification criteria for antiphospholipid syndrome diagnosis?

As discussed above, the goal of the APS classification criteria is to identify patients that have a high likelihood of having APS based on common and typical APS-related clinical manifestations. A common misconception is that the classification criteria for APS should also be used as diagnostic criteria. Although APS classification criteria may guide physicians in making a diagnosis, it should not be substituted for a doctor's clinical judgment, which is based on a complete evaluation of the patient.

What are the recent efforts to improve antiphospholipid syndrome diagnosis?

There are efforts to develop new tests to diagnose APS. Antiphosphatidylserine/prothrombin antibodies or anti-Domain-I antibodies are two tests that may be used more commonly in the future; however, more clinical studies are required to understand their potential diagnostic role.

One of my antiphospholipid antibody tests came back positive, do I have antiphospholipid syndrome?

As discussed above in question 3, the aPL laboratory profile assessment is critical. Depending on the type, subtype, level and persistence of the aPL laboratory tests, patients may or may not have a "clinically significant" aPL profile.

Even if you have a clinically significant aPL profile, it does not mean that you have APS. There are patients without any symptoms that have positive aPL. This condition is commonly referred to as "asymptomatic aPL positivity".

In summary, a full assessment should be performed by your doctor taking into account your medical history along with your aPL test results.

My lupus anticoagulant test is positive. Do I have lupus?

Not necessarily. Lupus anticoagulant is one of the tests to detect aPL. The reason why it is named "lupus anticoagulant" is because the discovery of the test was originally made in lupus patients. However, our understanding of this test has since evolved and now we know that lupus anticoagulant positivity is not exclusive to lupus patients, and does not necessarily indicate that a person has lupus.

References

Updated: 11/29/2023

Authors

Mert Sevgi, MD

Former Academic Visitor, Department of Rheumatology, Hospital for Special Surgery

Yasaman Ahmadzadeh, MD

Former Visiting Research Fellow, Department of Rheumatology, Hospital for Special Surgery

Stephane Zuily, MD, PhD

Attending Cardiovascular Specialist, Nancy Academic Hospital

Professor of Medicine, School of Medicine of Nancy, Lorraine University, Nancy, France

Medha Barbhaiya, MD, MPH

Medha Barbhaiya, MD, MPH

Attending Physician, Hospital for Special Surgery

Assistant Professor of Medicine, Weill Cornell Medical College

Doruk Erkan, MD, MPH

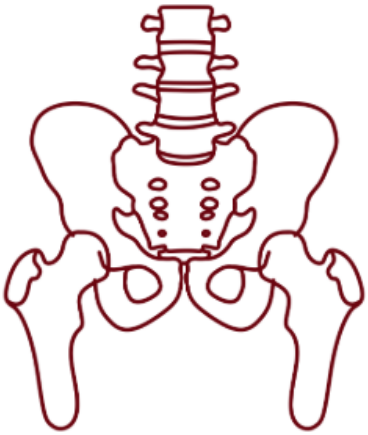
Doruk Erkan, MD, MPH

Attending Rheumatologist, Hospital for Special Surgery

Professor of Medicine, Weill Cornell Medical College

Republished with permission from Hospital for Special Surgery

What Can I do to Keep My Bones Healthy?
By MayoClinic.org



The following steps may help prevent or slow bone loss:

• Include plenty of calcium in your diet. For adults ages 19 to 50 and men ages 51 to 70, the Recommended Dietary Allowance (RDA) is 1,000 milligrams (mg) of calcium a day.

The recommendation goes to 1,200 mg a day for women age

51 and older and for men age 71 and older.

Good sources of calcium include dairy products, turnip greens, salmon and canned salmon with bones, sardines, tuna, and soy products, such as tofu. If it's hard to get enough calcium from your diet, ask your healthcare professional about taking a calcium supplement.

- Get enough vitamin D. Vitamin D helps the body absorb calcium. For adults ages 19 to 70, the RDA of vitamin D is 600 international units (IUs) a day. The recommendation goes to 800 IUs a day for adults age 71 and older.

Good sources of vitamin D include oily fish, such as salmon, trout, tuna and mackerel. Some foods also have vitamin D added to them, such as milk, cereals and orange juice. Sunlight helps the body make vitamin D too. If you're worried about getting enough vitamin D, ask your healthcare professional about taking a supplement.

• Stay active. Weight-bearing exercises can help you build strong bones and slow bone loss. Examples include brisk walking, jogging, dancing, climbing stairs, and playing soccer, tennis and pickleball.

• Don't use tobacco or drink too much. If you'd like help to stop using tobacco, talk to your healthcare professional. If you choose to drink alcohol, do so in moderation.

For healthy adults, that means up to one drink a day for women and up to two drinks a day for men.

• Ask about medicines. If you have to take any medicine for a long time, ask your healthcare professional if that might affect your bones. If so, talk about steps you can take to keep your bones healthy.

If you're worried about bone health or you have risk factors for osteoporosis, talk to your healthcare professional.

If you're worried about bone health or you have risk factors for osteoporosis, talk to your healthcare professional. Also talk to your healthcare professional about bone health if you break a bone when you're older than 50. You may need a bone density test. The results of that test show your level of bone density. The test results also can help your care team check your rate of bone loss and other measures of bone health. Using that information along with your risk factors, your healthcare professional can decide if medicine to help slow bone loss may be a good choice for you.

Who's Treating You? Your Guide to Some of the Professional Working in Your Physicians Office

Medical practices around the country increasingly rely on nurse practitioners, physician assistants and other health care professional to help with everything from monitoring vital signs to ordering tests, diagnosing illnesses and even assisting in surgery. These providers also play a critical role on the front lines of pain management and how to better take care of their health, Many are trained in what's known as the holistic model of nursing—an approach that's highly patient-focused; that different perspective can make nurse practitioners and other an impactful asset in the clinical setting. Here are some of the professionals you may you encounter in a doctor's office, who they are, and what they are trained to do.*

Registered Nurse (RN)

Registered nurses graduate from and approved nursing program and pass an exam to be licensed by a state board. They can administer medication prescribed by a physician or other health professional, monitor a patients vital signs and help educate the patient. They can help coordinate care, draw blood, insert intravenous lines and collect lab work.

What to Know: RNs can not perform some procedures without additional training and certification. They cannot prescribe medication.

Nurse Practitioner (NP)

Nurse practitioners have additional training to assess and address patient needs. NPs have a master's or doctoral degree and provide primary, acute and specialty health care. NPs take in medical histories, assess diagnose, order tests and x-rays, prescribe medications, and refer to specialists.

What to Know: NPs may work in specific subspecialities including pediatric, critical care, geriatrics, emergency care and other areas.

Physician Assistant / Associate (PA-C)

Licensed clinicians with a masters degree who practice medicine in an array of specialties. PAs take patient histories, assess and diagnose conditions, prescribe medications, and order tests. The main difference from a nurse practitioner is that PAs are trained according to the medical model while NPs are trained in the holistic nursing model of care.

What to Know: PAs nay work in a doctor's office, clinic or hospital setting under the supervision of a licensed doctor. They can also assist with surgery.

Certified Registered Nurse Anesthetist (CRNA)

Advanced practice registered nurses with specific training in anesthesiology, CRNAs have a master's or doctoral degree. CRNAs provide a full range of anesthesia and pain management services, the latter being particularly important for older adults who want to stay independent and active.

What to Know: CRNAs have a specialized training focused on administering anesthetic agents.

Advanced Practice Registered Nurse (APRN)

This title is an umbrella term covering four approved roles, including NPs, and CRNAs. They all earn a master's or doctoral degree in their specific area and they need to pass a certification examination. APRN's can can provide medical care during emergency situations.

What to Know: APRNs are trained in designed specialties.

*Responsibilities may vary based on state law

Source: aarp.org

The Present and Future of APS Research Continued

and thrombosis. This observation has led me to focus more closely on a specific ectonucleotidase called CD73, which produces the chemical adenosine to counteract inflammatory signals. As I continue to investigate APS platelets, I have identified promising new strategies to block their activation. I am now working to secure the funding necessary to extend these exciting concepts to patients living with this challenging condition.

Thalia Newman, MS (immunology graduate student): I'm about to start my third year of graduate school with Dr. Knight as my primary mentor. I'm motivated to investigate how fundamental laboratory discoveries can impact patient care. I am currently working to update important work that our team published ten years ago about spider web-like structures called neutrophil extracellular traps (NETs). The early results have hinted that a process called palmitoylation may be a new drug target, and I am now working with Dr. Knight to secure the funding necessary to support my next two years of graduate studies.

Yiran Shen, PhD (postdoctoral fellow): Since joining the APS research team in 2024, I've been exploring new ways to characterize the autoantibodies that cause disease manifestations in people with APS. My goal is to understand the origin of these harmful antibodies and how they function. Looking ahead, I hope that by applying modern tools for analyzing B cells to APS, we will identify new strategies for blocking the "bad" antibodies without interfering with the ones that keep us healthy.

Ajay Tambralli, MD (faculty member): In the past year, I have become increasingly interested in how metabolism (the process by which cells produce and utilize energy) might be optimized in patients with APS. In 2024, I found that neutrophils (immune cells often considered a major problem in APS) are highly proficient in utilizing glycolysis. Glycolysis is an efficient way for neutrophils to turn sugar into energy, but it carries the risk of making them overactive, which can lead to the formation of dangerous blood clots. I am now working toward understanding the links between metabolism and neutrophil behavior, which I believe will uncover new ways to "reset" or calm these cells. This could open the door to better, more targeted treatments for APS, ones that go beyond just using blood thinners and actually address the root cause of the condition. My long-term goal is to eventually be able to offer patients specific dietary recommendations based on any abnormalities I find in their blood.

Yu (Ray) Zuo, MD, MS (faculty member): APS is an autoimmune condition that affects patients differently, likely due to each individual's unique genetic and molecular makeup. A recent review in The Lancet Rheumatology highlights how advanced technologies, such as gene profiling and specialized lab tests, are helping us better understand different APS subtypes. Our team's own research, utilizing artificial intelligence to analyze gene-expression patterns, has identified four distinct patient subgroups under the umbrella of APS. By combining clinical assessments with this advanced testing, we aim to eventually develop personalized treatments that are more effective and have fewer side effects. I believe this integrated approach represents the future of APS care.

I Live with Both APS & Factor V Leiden by Eloise

It was December 2020, and I was about four weeks pregnant. I spent much time lounging on the sofa during the festive break. One day, I noticed my arm began to feel tight and stiff, but I put it down to my lounging and holding my phone.

Around a week passed, and my arm became so tight that I couldn't straighten it, and I noticed it was swollen, red, and warm. I visited the doctor, thinking it may be a bad bite. They did some blood tests, followed by a scan, and confirmed a blood clot in my arm.

I was treated with blood-thinning injections for the remainder of my pregnancy and six weeks after. I didn't have any further tests at this stage, and they never confirmed why I developed one, just that pregnancy was probably the cause.

Fast forward to June 2023, I started a new job that meant I was walking more. I noticed my calf was cramping, and I was limping. I assumed it was from being active, but when I noticed how swollen and red my leg was, my gut sank, and I knew I had another clot.

As this clot was my second, the doctors ran tests and found out I have factor V Leiden (heterozygous) and said I would be on blood thinners for life.

I became pregnant again and sadly suffered a miscarriage, which prompted my doctors to do a test for antiphospholipid syndrome (APS), which came back positive.

I now live with both APS and factor V Leiden, two things I had never heard of before, and my specialist put me on a trial of no blood thinning medication, which makes me nervous.

If I have any aches or swelling, I will always get checked out, as it's best to be on the safe side with blood clots!

The personal story is intended for informational purposes only.

Citation: Stop The Clot

APS at CARRA
By Jacqueline Madison, MD

As both an adult and pediatric rheumatologist, I, like many of my colleagues in pediatric rheumatology who work in research, am a member of the Childhood Arthritis and Rheumatology Research Alliance (CARRA). CARRA connects rheumatologists from across North America interested in pediatric rheumatology research. Earlier this month, CARRA held its Annual Scientific Meeting in Denver, Colorado.

Along with pediatric rheumatologists Dr. Deborah McCurdy and Dr. Elizabeth Sloan, I lead the APS Workgroup, which is closely affiliated with CARRA's SLE (lupus) Committee. Throughout the year, our group meets monthly to talk about active research projects and brainstorm new ideas. The CARRA Annual Scientific Meeting importantly allows us to gather in the same room, recruit new members, and hear from patient advocates about their priorities and ideas for pediatric APS research. It is a unique opportunity to come together.

This year, I had the chance to organize the meeting of the APS Workgroup. We started with a brief introduction to pediatric APS and some of its unique challenges, which I have outlined in a previous APS 101 blog post. A special guest, the mother of a pediatric APS patient, then shared the story of her young daughter's experience with APS, including catastrophic APS and adrenal insufficiency. Hearing the stories of our patients and their families inspires us to work even harder to be able to provide better solutions for quicker diagnosis and more comprehensive treatment.

Next, we gave updates on active projects in our working group. I shared the exciting work we are doing across multiple sites to assess how well the 2023 ACR/EULAR APS classification criteria apply to pediatric APS. The work is ongoing and supported by a grant from CARRA. More and more collaborators are joining this substantial undertaking, and I will report results in a future post! Dr. Sloan shared the details of her project, supported by a grant from CARRA-PreS (Pediatric Rheumatology European Society), to improve data collection in pediatric APS research. The goal is to create a set of research components that can be used consistently worldwide so that we are all collecting relatively uniform data variables when studying pediatric APS. It was because of this project that I traveled to Slovenia earlier this year to meet with other international pediatric APS experts. Both of these projects had posters at the CARRA Annual Scientific Meeting to share our findings beyond our working group.

Finally, the group worked together on another project supported by CARRA. There are few guidelines about the diagnosis and treatment of pediatric APS, and we do not know how rheumatologists across North America approach this disease or even whether it is mostly managed by rheumatologists or hematologists. To answer at least some of our questions about how providers identify and manage APS, we are developing a survey that will be distributed to pediatric rheumatologists and hematologists. At the meeting, we worked together to decide on the best questions to ask. The survey will be going out soon, and I also hope to provide an update on this project later this year!

Across the entire CARRA meeting, APS came up multiple times as an area of interest and unmet need as different researchers with different areas of expertise discussed their ideas. Overall, this meeting reinforced for me the significant enthusiasm and importance in collaborative research that I am confident will eventually lead to better outcomes for our APS patients!

I wish to acknowledge CARRA and the ongoing Arthritis Foundation financial support of CARRA. I also wish to acknowledge the ongoing contributions of the CARRA APS Workgroup.

Biologic Therapy Significantly Improves Pregnancy Outcomes in Women with Antiphospholipid Syndrome at High Risk for Serious Complications According to Hospital for Special Surgery

NEW YORK--(BUSINESS WIRE)--A landmark clinical trial co-led by Hospital for Special Surgery (HSS) has found that blocking inflammation with the drug certolizumab significantly reduces the risk of serious adverse pregnancy outcomes in women with antiphospholipid syndrome (APS).

The phase 2 IMPACT Trial (IMProve Pregnancy in APS with Certolizumab Therapy) was co-led by Jane E. Salmon, MD, a rheumatologist and the Collette Kean Research Chair at HSS, and D. Ware Branch, MD, an obstetrician/gynecologist at University of Utah Health. It is the first clinical trial to evaluate a biologic therapy to prevent serious adverse outcomes in pregnant women with APS and their babies. The study results were published online on April 10, 2025 in Annals of the Rheumatic Diseases.

"The IMPACT study represents a bold and very successful partnership over many years between government, industry, foundations, and academic health research institutions," said Dr. Salmon, the senior study author. "It is exciting to see our preclinical work in the laboratory, which began more than a decade ago, translate into such promising results for patients. I hope our findings will allow the drug to become widely available so that more pregnant women with APS and high-risk pregnancies can benefit."

APS is a rare autoimmune disorder affecting up to 0.05% of people. It is frequently associated with lupus, a disease most prevalent in women during their reproductive years. In APS, the body produces autoantibodies that react with blood vessels and circulating cells, causing dangerous blood clots throughout the body, which can lead to strokes, heart attacks, and phlebitis. During pregnancy, APS raises the risk of serious complications arising from issues with the placenta, including fetal death, preeclampsia, and restricted fetal growth.

Previous research led by Dr. Salmon identified lupus anticoagulant (LA), an autoantibody produced by some APS patients, as the strongest predictor of poor pregnancy outcomes in APS patients. Historically, 39% to 86% of pregnant women with APS who are LA positive have faced severe complications, despite treatment with standard-of-care blood thinners like heparin and aspirin. These patients have the greatest need for better treatments.

Dr. Salmon's preclinical research in experimental models showed that inflammation in the developing placenta, not blood clots, was the main cause of pregnancy complications in APS. This pivotal discovery led her team to investigate whether TNF-alpha inhibitors, a class of drugs used to treat inflammatory conditions like rheumatoid arthritis, Crohn's disease and plaque psoriasis, could offer better protection to APS pregnancies than blood thinners alone.

The IMPACT trial enrolled 51 pregnant women ages 18 to 40 with high-risk APS, defined as positive for lupus anticoagulant. All participants were treated with certolizumab, a TNF-alpha inhibitor that does not cross the placenta, in addition to standard-of-care heparin and aspirin, starting at week eight of pregnancy. Medication was stopped at week 28, the point at which the placenta is well-developed. The unique design of the IMPACT study made it possible for pregnant patients from 16 states and one Canadian province to participate.

The 20% complication rate in patients treated with certolizumab was dramatically lower than their prior pregnancies in which 69% to 79% had severe adverse outcomes, despite standard treatment with heparin and aspirin. The average gestational of age at delivery was 36.5 weeks in certolizumab-treated pregnancies, compared to 24 weeks in patients' prior pregnancies. Among IMPACT participants, 93% brought home a healthy baby—a remarkable improvement over the 38% survival rate for their previous pregnancies. Notably, none experienced serious infections or lupus flares, a concern when the study began.

The trial supports the concept derived from basic laboratory studies that targeting inflammation, rather than blood clotting, is effective in preventing pregnancy complications in high-risk pregnant patients with APS. It also shows the power of collaboration between rheumatologists and obstetricians.

"Our study heralds a new era for trials with biologics to prevent adverse pregnancy outcomes. We have shown that it is possible to gain the confidence of regulators and the trust of pregnant women who will enroll in clinical trials," said Dr. Salmon. "We are grateful to the patients and their care providers, who were committed partners in this trial, and to our funders who watched our trial with anticipation and excitement," said Dr. Salmon.

"These results also open a window for studying whether TNF-alpha blockade could help prevent preeclampsia in women without autoimmune disorders," she added. "Preeclampsia is the most common cause of morbidity and mortality of pregnant women and their babies, and there are currently no effective therapies."

The study was supported by funding from the National Institutes of Health, the Lupus Foundation of America, the Morris and Alma Schapiro Fund, the James R. and Jo Scott Research Endowment at the University of Utah and UCB Inc., the maker of certolizumab (Cimzia).

I Learned to Live Life with Less Stress and More Peace

By Dustin

In January 2022, at 27 years old, I checked into the hospital and was treated for a superficial clot in my right leg, along with a minor case of cellulitis, a bacterial skin infection.

Over the next few months, the pains in my leg continued to the point where I could no longer walk. I was put on apixaban and seen by a vascular doctor, but the pains didn't subside.

In April 2022, I checked into the hospital, where it was found that I had a DVT in my right leg, along with vasculitis, a condition that can trigger blood clots in which the blood vessels become inflamed, causing damage to the vessel walls. The vasculitis was not prioritized at the time, but it was causing most of my pain. I was placed on rivaroxaban and set up with a hematologist, who diagnosed me with antiphospholipid syndrome (APS).

Over the next two years, I lived my life as normally as I could, though I was still experiencing joint pains and the occasional swelling in my right leg, as well as frequent skin nodules.

In late March/early April 2024, I lost the ability to walk due to the skin nodules and swelling on my right leg. I checked into the hospital, where it was found that the rivaroxaban had failed, and I had a 2.5-foot-long clot spanning from my ankle to my knee.

I was immediately sent in for a thrombectomy to have most of the clot removed. Along with this, I was switched to warfarin, which I still take to this day.

In October 2024, I was back in the hospital with a major flare-up of vasculitis and was given prednisone and antibiotics to curb the pain.

Now, I see a rheumatologist and dermatologist to treat the vasculitis, and we are trying to determine why it typically flares up with blood clotting.

I've had a few drops in my INR, which put me back in the hospital in April 2025, but luckily, there were no acute DVT findings. It's a constant battle that brings me closer to an answer with each visit. There are no hereditary traits that relate to my blood clotting. It is 100% random.

I used to be a mountain climber and a lover of contact sports. I can no longer participate in these things due to the risk of bleeding and pain. I'm fatigued more often than other people my age, and my social life has taken a significant dip because I constantly need rest between work.

I've learned to accept death, as well as put things in perspective. Menial things are silly to me now, and it's easier not to take everything so seriously. In many ways, I've learned to live life with less stress and more peace.

My advice is to seek out help as soon as possible. Don't wait for things to get worse, and don't understate all your pain. The more the doctors can understand, the quicker they can help you, even if the constant re-explaining becomes exhausting.

Citation: Stop the Clot

Shopify Gift Shoppe

Written by Carla Moore

We would like to introduce you to our Shopify Gift Shoppe.

We are now offering items that represent APS, Lupus and our mascot, the dragonfly and our color burgundy.

Once the items are out of gone they are gone. So if you see them, order them before they are gone. 100% of the profits from these products will go to the

APS Foundation of America, Inc.

Visit our shoppe at:

https://apsfa.myshopify.com

Use code JUNE30 to save 30% on orders over $20.

Gardening With Arthritis: Tips for Preventing Joint Pain
Written By: arthritis.org

With a few adaptations, you can reap the benefits of gardening with less arthritis joint pain. Gardening can be a healthy hobby, especially when living with arthritis, providing both physical and mental health benefits. To continue gardening with arthritis, you only need a little planning and creativity to reduce the risk of joint pain and injury.

A few shortcuts and adaptations can make gardening possible for anyone, says Heidi Sibert, a landscape architect at James Martin Associates in Chicago. Sibert, who has psoriatic arthritis, is passionate about a horticultural approach called enabling gardens. Enabling gardens, which many doctors use as a form of physical, mental and social therapy, are designed to be accessible to people with specific needs and limitations. The key to gardening with arthritis is to keep your garden within easy reach.

With just a few adjustments or modifications, you can garden on any scale and indulge your preference for flowers, vegetables r landscaping plants. Start by identifying any potential limitations and finding a way around each one — modify gardening tasks as needed. Here are a few ideas to get you started.

Take Your Garden to a Higher Level

If you find it difficult to bend or stoop to work in your garden, bring it closer to you! Try a flower box or raised flowerbed to eliminate stooping. Raised beds, containers, or planting tables can also reduce the stress on your knees when you're digging, planting, weeding, and watering.

Raised beds can be made permanent, held up by wood, brick, or stone walls that will stay in place long-term. Consider hiring someone to help with the initial installation; once in place, the garden is yours to plant and enjoy.

You can grow your garden in pots or other containers for a more temporary or portable solution. Container gardens are especially great for apartments and small yards. For plants that you plan to move, save your joints by using lightweight Styrofoam or plastic pots. If they're big, fill them 1/3 full with Styrofoam peanuts, which will help with drainage and reduce their weight.

Use Joint-Friendly Tools

Long-handled tools that allow you to stand, not stoop, and easy-to-grip hand tools are all gardeners' friends. You can add attachments that lengthen tool handles to gain leverage.

Buy a kneeling pad or scooter wagon you can sit on while weeding. This will limit stooping and bending but be sure to stand up and stretch out occasionally. With other joint-friendly tools, you can enjoy gardening with less pain.

A wagon or yard cart with two wheels may be easier to maneuver than a wheelbarrow (with one wheel) when moving garden supplies and debris.

Practice Correct Posture

Let your larger/stronger joints do the work when possible. Instead of using your fingers to lift an object, try using the flat palm of your hand, your forearms or even your elbows. Practice good lifting posture — bending at the knees — when lifting keep items close to your body as you lift and carry them. Stand or sit up straight while you work and change positions often.

Take Frequent Breaks

When gardening, arthritis pain can build if you don't rest your joints properly. Stop and smell the roses and have a glass of lemonade. Well-earned, frequent breaks allow you to appreciate your garden's beauty, plan your next tasks, and get more done before fatigue begins. Doing so will help you maximize both the physical and mental health benefits of gardening.

APS Foundation of America
Post Office Box 801
La Crosse, WI 54602-0801

Phone: 608-782-2626
E-mail: apsfa@apsfa.org
Website: https://apsfa.org
Facebook: www.facebook.com/APSFA

FIRST
CLASS
STAMP

Find us online!
https://apsfa.org

APS Foundation of America

Antiphospho.....what?!?!

Sponsored by: **OPEN**

CaféPress ~ APS, DVT & Lupus Awareness Items

We have a number of new products & designs for DVT and Lupus Awareness Items available in our Café Press store. Some of our new products and designs are shown here and many are available in burgundy for APS as well. Our creative team is working on new one of a kind designs and lines and many more will be coming soon. There are even a few new items such as travel mugs, glasses, cellphone & iPad accessories, pillows, and dark colored shirts and sweatshirts.

Our Café Press items are high quality and the clothing comes in a variety of sizes from infant to many different adult sizes, including plus sizes and maternity. Many items also come in a variety of colors. The APSFA gets to keep a small percentage of each sale from our store when you buy from it, so not only will you get a quality item, but you will also make a donation to a worthy cause!! Check out our store at the address below and be sure to check back often.

https://www.cafepress.com/apsfoundation