



# ANTIPHOSPHO...WHAT?

APS Foundation of America, Inc. Newsletter

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



**A Joyous Holiday Season!**



## **APS 101 Series: Obstetric Antiphospholipid Syndrome by Jacqueline Madison, MD Clinical Assistant Professor**

The APS 101 Series, written by Jacqueline Madison, MD, takes you through the ins and outs of APS, providing facts and key information to help you better understand the disorder. In this month's edition, Dr. Madison discusses obstetric antiphospholipid syndrome, issues that can arise, and treatment strategies.

### **Obstetric Antiphospholipid Syndrome**

In this blog series, I have talked a lot about thrombotic APS including different types of blood clots, how to figure out if you have a blood clot, and ways to treat and prevent blood clots. It is important that we also discuss obstetric (pregnancy-related) problems associated with APS.

For some patients, their APS is identified when they have difficulties with pregnancy, either becoming or staying pregnant. Others may already know they have APS, but need to learn about potential pregnancy issues as they approach pregnancy.

### **Potential pregnancy issues**

So, what are the different issues that arise in APS pregnancies? The new 2023 ACR/EULAR APS classification criteria identify several problems in pregnancy known to be related to APS1. While the criteria do not cover every possible scenario, they highlight the most common issues we see in our patients.

One reminder: these criteria are made for classification, which means defining APS for research purposes, not diagnosis. Diagnosis can only be done by your doctor.

These new criteria are different than the previous criteria, which I discussed in a blog post in December 2021, so now is a good time to review.

### **Early pregnancy losses**

Sometimes APS is first identified when someone has recurrent early miscarriages and no other reason for them. Different terms are used for these early losses. In the APS criteria, they are defined as being either pre-fetal (under 10 weeks gestation) or early fetal (10 weeks through 15 weeks gestation). Multiple losses "count," so to speak, towards a classification of APS if they are consecutive, or all in a row.

If there are healthy pregnancies in between miscarriages, that is a pattern less specific for APS. If early pregnancy losses are the first symptoms of APS, the issue is most likely to be identified by our colleagues in obstetrics and gynecology. If antiphospholipid antibodies are detected, we, rheumatologists specializing in APS, typically get the call to evaluate the situation.

Because there are unfortunately many other causes of early miscarriages, this pattern of problems is not as specific for APS as they are for severe preeclampsia or placental insufficiency, which I talk about below.

### **Later pregnancy loss without another cause**

Unfortunately, sometimes APS is not identified until after a late pregnancy loss, which can be devastating. Testing after a case of late fetal death (defined in the APS criteria as 16 weeks or later) is sometimes how APS is identified. However, in the absence of preeclampsia or placental insufficiency, it is important to look carefully for other causes of the loss because there are a lot of other possible causes.

### **Severe preeclampsia or placental insufficiency**

These types of problems are felt to be the most specific for APS, especially when they lead to delivery before 34 weeks gestation.

For our purposes, preeclampsia means that a pregnant patient has both high blood pressure ( $>140/90$ ) and high protein in their urine. It is considered "severe" when there is one additional problem: even higher blood pressure ( $>160/110$ ), new headache, change in vision, fluid in the lungs, liver problems, kidney dysfunction, or low platelets ( $<100$ ).

Placental insufficiency means that the placenta, which provides oxygen and nutrients to the growing fetus, is not working normally. Placental insufficiency is called "severe" when there are signs that the fetus is not growing well based on their size (under the 10th percentile) combined with at least one other problem: abnormal fetal surveillance test (like a non-stress test), abnormal testing of blood flow to the baby (Doppler testing), severe growth restriction (less than the 3rd percentile), or not enough amniotic fluid (oligohydramnios).

Sometimes it can be difficult to diagnose a patient with obstetric APS if they have not also had blood clots. That's

**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](mailto:articles@apsfa.org) and we will send you our guidelines.

**Without your help our newsletter  
cannot be a success!**

### **Inside this issue:**

Obstetric APS	1
Letter from the President	2
Giving Tree	3
Grief and 988	4
Hair Loss	5
Winter Dry Eye	7
Caregivers Cornet	8
Dione's Story	9
Jillian's Story	10
APS & Kidney's	11
Handle Your Medications Safely	12
Shopify Gift Shoppe	12
NOAC vs Warfarin	13
Café Press	14



## Letter from the President



November is here and we are first dusting of snow in Wisconsin. Ever since I broke my ankle, snow and ice do not like each other.

We have been busy networking with other organizations like CARRA, Autoimmune Association, ITSH, World Thrombosis Day, ICAPA, Defense Health Research Consortium 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.

We are 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](mailto:apsfa@apsfa.org)

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](mailto: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**

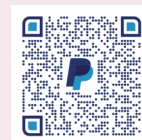
Division of Rheumatology & Immunology  
University of North Carolina at Chapel Hill

The information in this newsletter is not intended to replace standard doctor-patient visits. All information should be confirmed with your personal doctor. Always see the advice of a trained physician in person before seeking any new treatment regarding your medical diagnosis or condition. Any information received from the APS Foundation of America, Inc. through this newsletter is not intended to diagnose, treat, or cure and is for informational purposes only.

**If you have a medical emergency, please call your doctor or 911 immediately.**

All of the information in this newsletter is the property of the APSFA and © of the authors.

**Donate Today to the APS Foundation of America, Inc.**





## APSFA Giving Tree

This tree holds a special meaning for the members of the APS Foundation of America and the community it serves. Since the Giving Tree have been such a big success in the past, we have brought it back in an annual tradition and is our main end of the year fundraiser.

**How it works:** Donations are made using the buttons on the **Giving Tree page** at <https://apsfa.org/donate/2024-giving-tree/>.

There is an ornament or gift that corresponds with different donation amounts. The Giving Tree starts out bare but as the month progresses, the tree is decorated with generous donations.

At the end of the fundraiser, our tree is beautifully decorated with ornaments and gifts are spilling from beneath it.

If you prefer to remain anonymous, please let us know.

All Giving Tree donations (as long as they are completed by **12/31/2024**) are 100% tax deductible. Donation over \$200 through PayPal will an APS tote from our CafePress Store valued at \$18.00 USD while supplies last.



get bag

This years tree.





## Grief Over the Holidays

One of the greatest holiday stresses is the absence of a loved one who passed away. The empty seat where they would have sat can fill families with a sense of grief, loss and emptiness, as well as worsen symptoms for individuals with mental illness.

The following recommendations can help you and your family cope:

- It's not all sad. Know that some parts of the holiday will be wonderful, and some parts will be sad. The anticipation of sadness may be stressful, but the holidays provide an opportunity for healing. You can still take joy in the relatives that are present and remember fond memories of holidays past.
- It is okay to feel the way you feel. It is healthy to acknowledge your feelings and work through them, rather than suppressing them.



- Take care of yourself. Find healthy ways to cope, such as exercising. Organizing family walks is a great way to get fresh air and enjoy the company of others. Don't search for solace in unhealthy foods or alcohol. If alcohol is present, drink responsibly.

- Don't feel pressured to uphold family traditions. While they might be a comforting way to remember a loved one, sometimes family traditions are too painful to bear. Your family will find new ways to celebrate, and your traditions will adjust with time.

Keep in mind that the loved ones you lost would want you to remember them fondly, to enjoy the holiday season, and to find comfort in having the family come together.

Source: [www.nami.org](http://www.nami.org)

## Seasonal Blues

As temperatures drop, many of us may be dreading the impending mood changes that can accompany weather changes. If you go through periods of feeling sad, less motivated, or not like yourself as it gets colder and daylight gets shorter, you are not alone. This is a common occurrence and is often referred to as "Winter Blues." If you experience Winter Blues, consider what self-care ideas might be helpful to you.

Talk to a trusted individual about how you are feeling. Take part in activities that make you feel good. Go to a movie, volunteer, create art, bake cookies, etc. Get regular exercise. Soak up natural light whenever you get a chance. Eat whole, healthy, well-balanced meals. Break down your to-do list into smaller tasks and celebrate when you complete one task. Get outside, even if just for a little bit, and even if it's cold. Plan things you will look forward to. Socialize with friends, family, and your community. Find something to be grateful for every day, even if just a warm cup of hot chocolate.

If your mood and/or behavior changes are more serious and impact your ability to function on a day-to-day basis, you could be experiencing Seasonal Affective Disorder (also

known as "SAD"). SAD is a type of depression that presents in a recurring seasonal pattern. Whether the Winter Blues or SAD, if you or someone you know needs help, 988 can connect you with resources. Peer support, therapy, and medication are common types of support and treatment. Text, call, chat, or search our public database for what options might be available in your area.



Simply Dial 988. Get Connected, Professionally trained staff can answer your questions about local, statewide, and national resources and can assist you with life situations and challenges. Available 24 hours a day, 7 days a week. Free and Confidential. Language Interpretation is available.





## Eight Reasons Women Lose Their Hair

By Michelle Crouch, AARP

The most common causes of hair loss in women and how to get your hair back if it's happening to you.

If you've ever ended up with a big handful of hair in the shower, you know the panic that can instill. Suddenly, you're analyzing the ratio of hair to scalp on your head — can you see more of your scalp than you used to? Is your part getting wider? Could you be losing your hair?

Many women experience hair loss and hair thinning as they get older, says Maria Colavincenzo, M.D., a dermatologist who runs a clinic focused on hair and scalp disorders at Northwestern Medicine. A 2022 study published in the journal *Menopause* found that 52 percent of postmenopausal women had hair thinning or hair loss.

Hair loss — also called alopecia — can be especially difficult for women because it isn't as cosmetically acceptable as hair loss in men, Colavincenzo says.

"There isn't an attractive shaved head look for women," she says. "Women [with hair loss] go through great pains to cover it up using camouflage agents like hair powders and agents. They often feel very isolated."

What's normal, what's not

While some hair loss is normal with aging, sudden or excessive hair loss, bald patches and hair loss that accompanies a rash, flaking or itchiness are not. Those can be signs of a more serious condition and should be evaluated by a doctor.

"It is a good idea to check with your dermatologist if you notice a significant amount of hair loss," says Shoshana Marmon, M.D., assistant professor of dermatology at New York Medical College.

An accurate diagnosis is important, Marmon says, because the treatment can vary greatly depending on what is causing the problem.

Here are some of the most common reasons women lose their hair, and what you should know about each:

### 1. Genetics

The most common cause of hair loss among older women is called female pattern hair loss, or androgenetic alopecia.

It's the "lady's version" of the genetic condition that causes men to go bald, Colavincenzo says.

Female pattern hair loss is caused by inherited genes that make hair follicles shrink and eventually stop growing hair. You may notice that your part is gradually becoming wider, that your ponytail is thinner or that the hair near your temples has started to recede.

As with men, your genetics determine how badly the condition affects you. It's rare for a woman to lose all of her hair, according to the American Academy of Dermatology.

"Unlike men who get a receding hairline or a bald spot, in women it's often more diffuse, where the hair on the whole top area of the head is a little thinner," Colavincenzo says.

A variety of treatments can help stop or

slow genetic hair loss, including over-the-counter 5 percent minoxidil solution (Rogaine), prescription medications, laser therapy and different types of scalp injections.

### 2. Illness, surgery or rapid weight loss

When your body is under physical duress — such as when it is fighting an infection or recovering from surgery — you can end

up with a lot of hair shedding, says Lauren Eckert Ploch, M.D., a board-certified dermatologist in Aiken, South Carolina.

"Basically, the body can't handle doing too many things at once," Ploch says. "When there is a stressful event, your body says, 'I'm going to stop devoting resources to hair growth and focus on

this illness.'"

Usually, hair starts to fall out two to three months after the event, Ploch says. You may even notice handfuls of hair coming out when you shower or brush your hair.

Called telogen effluvium, the condition happens a lot after people have COVID-19, Ploch says. You can also lose hair after a bout with the flu or pneumonia, a major surgery or a large amount of weight loss. In fact, many people who have lost a lot of weight after taking the new GLP-1 drugs such as Ozempic or Wegovy experience hair loss.

Fortunately, telogen effluvium is temporary, Ploch says. Your hair should go back





to normal in about six to nine months if you stop taking the medication.

### 3. Emotional stress

Psychological distress can also cause hair to fall out, another form of telogen effluvium, Colavincenzo says. She has seen patients shed hair after divorce, the loss of a loved one or a layoff. Hair loss is also common in caregivers because of the stress they are under, she says.

"People talk about the three B's: bereavement, breakup and bankruptcy," she says. "Anyone dealing with a big stress in their life can have hair shedding."

Colavincenzo says she often refers those patients to a mental health provider for treatment. Fortunately, their hair typically grows back once their stress is relieved or they figure out how to manage it.

### 4. Thyroid imbalances

Your thyroid is a butterfly-shaped gland at the base of your neck that plays a role in many bodily functions, including the development and maintenance of hair follicles.

"The thyroid is like the driver of our body in many ways," Ploch says. "Thyroid hormone is important. If it's low, it will mimic a state similar to severe stress, so you can end up with some hair loss."

Studies show both an underactive thyroid and an overactive thyroid can contribute to hair loss. Women are more likely than men to develop thyroid problems.

Thyroid problems can affect your weight, sleep, energy level and mood. But because the signs are subtle, hair loss is sometimes the first symptom women notice, Colavincenzo says.

A simple blood test can measure thyroid hormones in your blood, and medication can treat an overactive or underactive thyroid. The hair loss should resolve once you treat the problem.

### 5. Vitamin or mineral deficiency

Some studies have indicated that a shortage of vitamin D, iron, protein or other nutrients could contribute to hair loss.

"Vitamin or mineral deficiencies deprive the hair of necessary nutrients,

weakening the hair structure and potentially interrupting normal hair growth," Marmon says.

Iron deficiency, in particular, has been linked to hair shedding.

If you notice hair loss, experts recommend as a first step asking your health care provider for a basic blood test to check for nutrient shortages.

It's not necessary to take a supplement unless a deficiency is identified, Colavincenzo says. In fact, getting too much of certain nutrients such as selenium, Vitamin A and Vitamin E may produce the opposite effect and cause you to lose hair.

### 6. Harsh hair styling or treatments

Sometimes, the way you treat your hair can damage the hair follicle and cause hair loss.

If you often wear your hair in a tight ponytail, bun or braids, if you get regular chemical treatments, if you often wear a weave, or if you subject your hair to frequent heat styling, you can cause breakage and hair loss that can become permanent if the behavior continues.

"Less is more when it comes to hair care," Ploch suggests. She recommends choos-

ing ammonia-free hair color if possible, and not wearing tightly pulled styles every day.

### 7. Alopecia areata, an autoimmune disease

Alopecia areata is a complex autoimmune disease that can cause bald spots.

When you have alopecia areata, your immune system attacks your hair follicles, shaving off the hairs underneath the skin. Hair typically falls out in small, round patches about the size of a quarter. In some cases, the amount of hair lost can be extreme.

There is no cure for alopecia areata, but new medications can help restore hair even when the condition is severe.

### 8. Scarring alopecia

This is a disease often caused by an autoimmune or inflammatory disorder that destroys your hair follicles and replaces them with scar tissue. It can be especially devastating because once the hair follicles are gone, "you can't get the hair back," Ploch says.

One common type of scarring alopecia affects your eyebrows and your front hairline first and then works its way toward the back of your head. Some patients with scarring alopecia also experience itching, pain or bumps in the affected area.

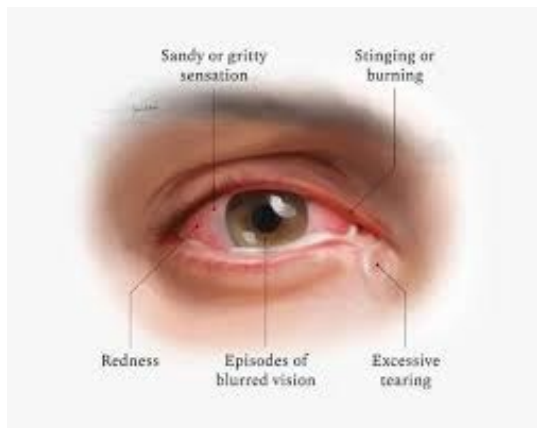
Scarring alopecia is usually diagnosed with a biopsy. Treatment should be immediate and aggressive, Ploch says.

**Michelle Crouch is a contributing writer who has covered health and personal finance for some of the nation's top consumer publications. Her work has appeared in Reader's Digest, Real Simple, Prevention, The Washington Post and The New York Times.**



## Eight Tips to Beat Winter Dry Eye

By: Tina Pohlman



One of the most common patient complaints during the winter months is dry eyes. In the cooler climates, cold winds and dry air,

coupled with dry indoor heating can be a recipe for eye discomfort.

Dryness and irritation can be particularly debilitating for those who wear contact lenses or suffer from chronic dry eyes – a condition in which the eyes produce a low-quality tear film.

Symptoms of Dry Eye- Harsh weather conditions can reduce the natural moisture in your eyes and the irritation usually results in a burning or itching sensation that often leads to rubbing or scratching your eyes which can worsen the symptoms. Sometimes it feels like there is a foreign object in your eye and for some, dry eyes can even cause excessive tearing, as your eyes try to overcompensate for their lack of protective tears. Prolonged, untreated dry eyes can lead to blurred vision as well.

Dry Eye Treatment- Whatever the symptoms, dry eyes can cause significant discomfort during the long winters and relief can seriously improve your quality of life.

Here are eight tips to keep your eyes comfortable during the harsh winter months:

1. **To keep eyes moist, apply artificial tears/eye drops a few times a day.** If you have chronic dry eyes, speak to your eye doctor about the best product for your condition.

2. **Drink a lot of fluids** – keeping your body hydrated will also help maintain the moisture in your eyes.

3. If you spend a lot of time indoors in heated environments, **use a humidifier** to add some moisture back into the air.

4. **Try to situate yourself away from sources of heat**, especially if they are blowing. While a nice cozy fire can add to the perfect winter evening, make sure to keep your distance so dry eyes don't ruin it.

5. Staring at a computer or digital device for extended amounts of time can further dry out your eyes. If you spend a lot of time staring at the screen, **make sure you blink often and practice the 20/20/20 rule** – every 20 minutes, look 20 feet away for 20 seconds.

**Dry Eye Treatment- Whatever the symptoms, dry eyes can cause significant discomfort during the long winters and relief can seriously improve your quality of life.**

6. **Don't rub your eyes!** This will only increase irritation and can also lead to infections if your hands are not clean.

7. **Give your eyes a break and break out your glasses.** If your contact lenses are causing further irritation, take a break and wear your glasses for a few days. Also, talk to your optometrist about

switching to contacts that are better for dry eyes.

8. **Protect your eyes.** If you know you are going to be venturing into harsh weather conditions, such as extreme cold or wind, make sure you wear protection. Try large, 100% UV protective eyeglasses and a hat with a visor to keep the wind and particles from getting near your eyes. If you are a winter sports enthusiast, make sure you wear well-fitted ski goggles.

If you find that after following these tips you continue to suffer, contact your eye doctors. It could be that your condition requires medical intervention.

Source: [www.theeyecenter.us](http://www.theeyecenter.us)



## Caregivers Corner: Resisting Care Reprint from Trualta



Have you ever tried to get your care recipient to shower when they don't want to?

Has your care recipient ever started acting aggressively when they don't want to do a task? Many caregivers believe that their care recipients are resisting care or being stubborn on purpose. However, your care recipient is likely not doing this on purpose. Instead, they are trying to communicate to you that something doesn't feel right. What can you do?

### Trigger Reduction

Your care recipient may be resisting care because they are trying to communicate that they have an unmet need, are overstimulated, or are uncomfortable. By identifying what might be wrong, or what the trigger is, you can help prevent resistance to care by reducing these triggers.

Ask yourself the following questions to help identify triggers:

- Are they too cold or too hot?
- Are they in pain?
- Are they afraid of something?
- Are they used to doing this task at a different time of day?

If your care recipient always resists doing the same task, you can ask yourself more specific questions to identify the trigger.

For example, if your care recipient often resists showering, you can ask yourself:

- Do they have any traumatic experiences with water, such as drowning?
- Do they have any traumatic experi-

ences related to privacy or consent, such as sexual assault?

- Are they feeling uncomfortable because they don't recognize the person that is helping them shower?
- Are they a very private or modest person?
- Is there something that could make them more comfortable in this situation?

Once you know what the trigger is, you can make specific changes to reduce that trigger.

For example, if your care recipient is afraid of the water, you can slowly increase their tolerance to it over time.

**Expert Tip:** Follow these steps to gradually increase tolerance to water in the shower:

- Start with a sink sponge bath.
- Next time, move closer to the shower.
- Next time, keep water off but sponge bath in shower.
- Next time, turn water on and sponge bath in shower without shower water connection.
- Next time, allow shower water to reach legs and sponge bath.
- Continue to gradually incorporate shower to desired comfort level.

Prepare to stop or pause if you notice signs of anxiety or fear in your care recipient.

A routine can help make care tasks more familiar and comfortable. This can help reduce resistance to care. When creating your care routine, consider things like:

- Does this task require a lot of energy? If so, at what time of day do they have the most energy?
- Have they done this task at a certain time of day their whole life?

For example, have they always showered in

the morning or at night?

- How long does this task take?
- When is it convenient for both you and your care recipient to do this task?
- Can this task be skipped? For example, showering can be skipped but taking heart medications can't be skipped.

### Environment Set Up

Your care recipient may not always understand what is happening. Setting up the environment with familiar items and creating a relaxing environment can help make them more comfortable and provide distraction. This can help reduce resistance to care.

For example, if your care recipient often resists showering, you can try:

- Giving them the same brand of shampoo, they have always used.
- Giving them a loofah or a washcloth, depending on what they are used to.
- Playing their favorite relaxing music.
- Turn the water on a few minutes before they come in so that the room warms up.
- Have all the necessary supplies nearby and ready for use so that they aren't waiting.

### Redirecting

If you have tried to identify and reduce triggers, establish a routine, and set up the environment but your care recipient still does not want to do the task, that is ok. Remember that it is their body, and they still have the right to say no. In these situations, it is best not to force the person. Instead, redirect them to a different activity or room and try to come back to the task later.





because many of these obstetric problems are also seen in patients with difficult pregnancies for other reasons.

We feel most definite about the APS diagnosis when blood testing for antiphospholipid antibodies is strongly positive or other parts of the person's history also point toward a diagnosis of APS. We have seen patients who had some of these obstetric problems years ago and then developed blood clots later in life. Only then, after putting the whole history together, did the medical team test for antiphospholipid antibodies.

#### Treatment strategies

There are treatment strategies to help patients achieve healthy (or at least healthier) pregnancies, so the first step is to identify obstetric APS. Our colleagues in obstetrics and gynecology often do an excellent job finding these at-risk patients, and when we work together, often with hematology also, we can diagnose obstetric APS and then come up with an individualized management plan<sup>2</sup>.

In patients with antiphospholipid antibodies, but no history of obstetric or thrombotic problems, low-dose aspirin is often the recommended treatment. For other patients, we recommend a combination of low-dose aspirin and a prophylactic dose of low-molecular-weight heparin (Lovenox). If patients have a history of a blood clot, then the dose of low-molecular-weight heparin will likely be higher. We always work very closely with hematology and obstetrics when making these decisions.

When patients need additional support, we sometimes recommend hydroxychloroquine, which is a lupus drug with a long track record of use during pregnancy. In addition to a diagnosis of lupus, other factors that point us toward hydroxychloroquine are very high antibody levels or ongoing difficulties despite aspirin and low-molecular-weight heparin.

Like for all patients with APS, we hope to increasingly personalize the treatment of obstetric APS, attacking underlying immune-mediated mechanisms. There is hope we will have new treatment options in the future.



For example, an ongoing trial is enrolling North American patients to test whether certolizumab (Cimzia) improves outcomes for obstetric APS. For pregnant individuals with APS and positive lupus anticoagulant testing, the trial is adding certolizumab to the usual treatments. Certolizumab inhibits an inflammatory molecule called TNF. It is commonly used for rheumatoid arthritis, especially during pregnancy where it is safer than alternative medications. More information can be found at [ClinicalTrials.gov](https://clinicaltrials.gov).

Pregnancy is a time of significant physiologic stress on the body, and it takes a team approach to diagnose and successfully treat this important and life-changing aspect of APS. We and others are working hard to improve

outcomes even further.

#### References:

Barbhaiya M, Zuily S, Naden R, et al. The 2023 ACR/EULAR Antiphospholipid Syndrome Classification Criteria. *Arthritis Rheumatol* 2023;75(10):1687-702. doi: 10.1002/art.42624 [published Online First: 2023/08/28]

Sammaritano LR, Bermas BL, Chakravarty EE, et al. 2020 American College of Rheumatology Guideline for the Management of Reproductive Health in Rheumatic and Musculoskeletal Diseases. *Arthritis Rheumatol* 2020;72(4):529-56. doi: 10.1002/art.41191 [published Online First: 2020/02/25]

## My APS Diagnosis Got Lost: Dione's Story By: Dione

In 1994, I had my son prematurely at 24 weeks. They did a bunch of testing and found out that I had antiphospholipid syndrome (APS).

I had another preterm baby at 25 weeks three years later. I was followed by a high-risk OB/GYN at the time but no other preventative measures were done while pregnant.

Over the years, my APS diagnosis got lost in my medical records. I always had joint pain and was prescribed anti-inflammatory medications. In 2021 I had a medial collateral ligament (MCL) surgery to repair a torn MCL ligament in the knee.

Within the first two weeks of the surgery, I had pain in my left calf. I thought it was related to the surgery. Within the next couple of weeks, I was getting shortness of breath to the point that walking down the stairs was a task.

Due to COVID, I went to a COVID clinic. They told me to get to the hospital. I was diagnosed with multiple bilateral PEs. All lobes were involved along with a saddle clot. I stayed in the ICU for three days.



NBCA resources helped put my APS diagnosis puzzle together. In the ICU, I read up on what a blood clot was. I came across an article on blood clots and APS. I mentioned to my pulmonologist that I was diagnosed with APS years earlier and he had me re-tested for it. It came back as triple positive.

This led to many hospital visits with a hematologist, rheumatologist, pulmonologist, and my PCP. I'm still on my journey to return to a healthier state, but it's getting easier now that I'm on hydroxychloroquine to help relieve inflammation and warfarin.

The personal story is intended for informational purposes only.



## **I Mistook My Symptoms as a Panic Attack: Jillian's Story by Jillian**



In December 2021, I was climbing up the subway stairs, heading to my college campus in New York City, when I started feeling off-balanced and dizzy.

I suffer from anxiety and panic attacks, so that's what I thought was happening. I sat down and a nice family came over to me and asked if I was okay. I told them I thought I was just having a panic attack, and they handed me a snack and bottle of water. I sat there for a little bit longer until I felt like I was okay to stand up again.

But I tried walking a little bit farther and realized I was not okay. I decided to go back to my dorm, so I called a cab, and I also called my parents to tell them what was going on. I was getting more out of breath and having sharp chest pains that worsened when I breathed in. I

was also coughing a lot and my mouth tasted like blood.

My parents told me that they wouldn't be able to get me until the next morning, so I tried waiting it out. I decided to go to sleep and see how I felt in the morning, and if I still wasn't okay, I would go to the hospital.

The next day I wasn't any better, so I went to the ER. After a bunch of tests, the doctors came in and told me that I had multiple bilateral pulmonary emboli in my lungs. I was told that if I had waited to come in, I would not still be here.

I was immediately put on heparin, an injectable anticoagulant until I was out of the hospital, then I was switched to an oral anticoagulant, rivaroxaban. The doctors told me that the estrogen-based contraceptive that I started taking in August 2021 was most likely the reason why I had these clots.

But my hematologist did more testing, and I was told that I also have a clotting disorder, antiphospholipid syndrome, making me predisposed to clots. I am now on anticoagulants for the rest of my life.

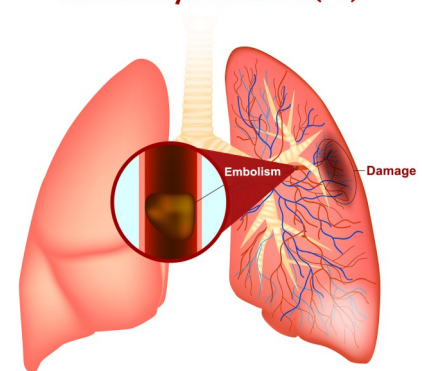
My lungs are weaker and contain scarring now. I am still out of breath a lot, so my pulmonologist gave me

an inhaler to use. I try and exercise, but even just walking longer distances can still be challenging.

Many NBCA resources have been useful to me, including the new [patient resource guide](#) and [PEP Talks](#) that take place over Zoom.

Since this experience, I've learned to take better care of my body and to be grateful every day that I am still here. My advice to others is to celebrate life, as you've gotten another chance at living it. It's going to be a long recovery, and it's not going to be easy, but you've got this!

### **Pulmonary Embolism (PE)**



The personal story is intended for informational purposes only.



## APS Program Community Q&A Series

### How does APS impact my kidneys, and how can I protect them?

By Ray Zuo, MD Associate Professor—University of Michigan



The APS Program Community Q&A Series, written by Yu (Ray) Zuo, MD, MSCS, was created to answer questions we receive from the APS Program community and covers a variety of topics. In this month's edition, Dr. Zuo discusses how APS can impact your kidneys and the steps that you can take to keep your kidneys healthy.

#### How does APS impact my kidneys?

Our kidneys represent a special filtering system that balances fluid levels, maintains blood pressure, and removes waste products from the blood.

Antiphospholipid syndrome (APS) can impact kidney health in various ways. It can cause blockages in the relatively large arteries and veins that supply the kidneys (though blood thinners typically do a good job of preventing such blockages).

APS can also affect the smaller blood vessels of the kidneys, which leads to a unique condition known as APS nephropathy. This entity was first identified in the 1990s when research studies observed microscopic blood clots in the kidney biopsies of some patients with positive testing for antiphospholipid antibodies (1). By 1999, preliminary criteria were established to distinguish APS nephropathy from other types of kidney disease based on unique findings under the microscope after a kidney biopsy (2).

Over the years, research has linked APS nephropathy to other aspects of APS, including previous strokes, livedoid skin rashes (red-purple blotchy skin), positive lupus anticoagulant testing, and catastrophic APS (1). A systematic review of the literature by an international task force led to the inclusion of APS nephropathy in the 2023 APS Classification Criteria, where the definitions of APS nephropathy were updated and refined (3, 4).

To make a diagnosis of APS nephropathy, either fresh or chronic changes should be present when the pathologist reviews the biopsy specimen under the microscope:

**Fresh (Acute) Changes:** These appear as sudden damage to the kidney's microscopic blood vessels and filters (glomeruli). Small clots made up

of a protein called fibrin are often appreciated. There should not be significant antibody or complement (a type of blood protein) deposits as one would expect in patients with lupus.

**Chronic Lesions:** These are longer-term changes in the kidneys that develop over months or years. Examples include old/healed clots, narrowing of blood vessels due to a build-up of scar tissue-like thickening in the vessel walls, shrinkage of kidney tissue, and changes in the kidney tubules that carry urine out of the kidneys.

Patients with APS nephropathy may present with new or worsening high blood pressure, microscopic blood in the urine, protein in the urine, and loss of the kidney's filtering efficiency as determined by blood tests. However, a kidney biopsy is the only way to make a sure diagnosis.

APS nephropathy is thought to be relatively rare, with an estimated prevalence amongst patients with APS of 10-20%. On average, such patients do seem to have worse outcomes compared to other APS, including the risk of progressing to end-stage renal disease requiring dialysis (5).

Though APS nephropathy does not have a standardized treatment protocol proved by clinical trials, some combination of anticoagulants and immunosuppressants is typically recommended. Recent research has also revealed promising new targets for treatment. Notably, our research group has identified a critical role for neutrophil extracellular traps (NETs) in causing vessel damage in APS patients, which appears to be a key factor in developing APS nephropathy (6). Whether new or repurposed treatments that disrupt NETs should be part of future treatment regimens is something we are actively studying (7).

#### What can I do to keep my kidneys healthy?

It is crucial to maintain control of other major risk factors for kidney problems, especially diabetes and high blood pressure. Both of these issues are well known to damage the kidney's filtering system, which can eventually lead to the kidneys having trouble removing wastes and extra fluid from your body. High blood pressure is an especially tricky situation since kidney problems lead to fluid and salt buildup that further raises blood pressure, creating a dangerous cycle. Fortunately,

some simple lifestyle factors can decrease the risk of kidney disease.

Here are some simple steps you can do to prevent kidney disease in APS:

Manage blood sugar and blood pressure effectively and proactively whenever possible.

Take APS medications as prescribed.

Choose a healthy diet low in processed foods, salt, and added sugar.

Get regular physical activity.

Maintain a healthy weight.

If you smoke, quit.

Ensure you get adequate sleep.

Although APS nephropathy is relatively rare, its onset can significantly worsen health outcomes, underscoring the importance of actively

monitoring and maintaining kidney health. Since kidney disease is almost always silent in its early stages, we monitor kidney function with blood and urine testing at most APS clinic visits. We encourage you to discuss your kidney health during your next medical visit. Early detection of kidney disease allows for earlier treatment, which is vital in protecting your kidneys.

#### References:

- Xourgia E, Tektonidou MG. Antiphospholipid syndrome nephropathy: Current knowledge and unanswered questions. Clin Immunol. 2023;255:109735.
- Nochy D, Daugas E, Droz D, Beaufrils H, Grunfeld JP, Piette JC, et al. The intrarenal vascular lesions associated with primary antiphospholipid syndrome. J Am Soc Nephrol. 1999;10(3):507-18.
- Barbhaiya M, Taghavi M, Zully S, Domingues V, Chock EY, Tektonidou MG, et al. Efforts to Better Characterize "Antiphospholipid Antibody Nephropathy" for the 2023 ACR/EULAR Antiphospholipid Syndrome Classification Criteria: Renal Pathology Subcommittee Report. J Rheumatol. 2024;51(2):150-9.
- Barbhaiya M, Zully S, Naden R, Hendry A, Manneville F, Amigo MC, et al. The 2023 ACR/EULAR Antiphospholipid Syndrome Classification Criteria. Arthritis Rheumatol. 2023;75(10):1687-702.
- Gaspar P, Sciascia S, Tektonidou MG. Epidemiology of antiphospholipid syndrome: macro- and microvascular manifestations. Rheumatology (Oxford). 2024;63(SI):SI24-SI36.
- Ambati A, Zuo Y, Knight JS. An update on inflammation in antiphospholipid syndrome. Curr Opin Rheumatol. 2023;35(2):89-97.
- Ambati A, Knight JS, Zuo Y. Antiphospholipid syndrome management: a 2023 update and practical algorithm-based approach. Curr Opin Rheumatol. 2023;35(3):149-60.





## Handle Your Medications Safely at Home

### By the GWAAR Legal Services Team

Keeping track of your medications can be complicated, especially if you are taking several prescription drugs for different medical conditions. Read on for tips on how to manage your medications safely.

**1. Follow your medication schedule, and take the proper dose.** Confirm the dose and when to take each medication with your doctor or pharmacist. Remember that some medications should be taken with food while others should be taken on an empty stomach. Make taking your medications part of your daily routine. For example, you might take them as soon as you get up, after brushing your teeth, or with breakfast. Write down your medication schedule if that will help you remember, or consider using a pill organizer with compartments for days of the week and times of day so you know whether you've taken your medication.

**2. Make sure all of your medical providers know what medications you take and whether you are allergic to any medications.** If you see different providers for different medical conditions, each provider might not know what the others have prescribed. Consider bringing a list of your medications and their dosages with you to appointments. Make sure your pharmacist knows about all of your prescriptions and over-the-counter medications. Filling all of your prescriptions at one pharmacy makes this easier.

**3. Talk to your medical providers about any possible side effects or medication interactions.** For example, some medications interact poorly with alcohol, so ask your doctor or pharmacist if it is safe to drink alcohol while taking your medication. In addition, know who to call if you have a bad reaction to any medication.

**4. Store and handle medications safely.** In general, you should keep them in a cool, dry place that is out of the reach of children. Some medications may need to be refrigerated. Medications that are not currently in your pillbox should be kept in their original containers. The labels on these containers have important information like the name of the medication, dosage, prescriber's name, and the expiration date. The labels might also tell you how to store the medication and what side effects may occur. Make sure you take your medication in a safe environment. For example, if you are in a room with poor lighting, or you are tired or distracted, you might take the wrong medication or the wrong dosage. Never take medication that was prescribed for someone else.



**5. If your doctor tells you to stop taking a medication, dispose of it immediately.** You should also dispose of any medications that have expired. Do not keep them because you think you may need them in the future, as medications that have expired or that you have been told to stop taking may cause bad side effects or interact with other medications. For example, the Wisconsin Department of Justice coordinates two drug take back days each year throughout the state. In addition, permanent drug drop boxes throughout the state are open year-round and can be found at hospitals, pharmacies, and police departments, as well as other locations.

Please note that you should never flush unused or expired prescription medications or pour them down a drain.

## Shopify Gift Shoppe

Written by Todd Ponagai

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 burgun-



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>





## NOAC vs. Warfarin for antiphospholipid syndrome: a pattern emerging? Written By: William Parker, MD



In the field of oral anticoagulation (OAC), great strides have been made in the last decades. Vitamin K antagonists (VKAs) such as warfarin were until recently the only option in this domain. A narrow therapeutic index and highly unpredictable pharmacokinetics make it difficult to be a patient on a VKA and difficult for health professionals to effectively administer

the treatment.

Large trials have demonstrated clear benefits of non-vitamin K antagonist OAC (NOACs) over VKAs in the most common indications for OAC such as non-valvular atrial fibrillation (AF) or venous thromboembolism (VTE), leading to both reduced bleeding and reduced thrombotic events. This is reflected in current ESC guidelines. However, there remain settings associated with particularly high thrombotic risk in which NOACs have not been well evaluated against VKAs, including those with mechanical heart valves, valvular AF (in the presence of at least moderate mitral stenosis) and thrombosis associated with thrombophilias such as antiphospholipid syndrome (APS). APS is an autoimmune disorder characterized by a combination of clinical thrombotic events and

laboratory evidence of the presence of lupus anticoagulant, anti-cardiolipin or anti- $\beta_2$  glycoprotein I antibodies. OAC with a VKA has generally been standard-of-care for patients with APS. However, use of a NOAC has been endorsed in some lower-risk cases or in those with absolute or relative contraindications to a VKA, though evidence supporting this approach has been relatively lacking.

The recent publication by Khairani and colleagues in the Journal of the American College of Cardiology reports their meta-analysis of data from a total of 472 participants of four open label randomized controlled trials comparing NOAC (either rivaroxaban or apixaban) with warfarin. They found that arterial thrombotic events occurred more commonly in those receiving NOAC (10.3 % vs. 1.3%, odds ratio [OR] 5.43 [95% CI 1.87 to 15.75],  $p < 0.001$ ). There was no significant difference in venous thrombotic events (1.20 [0.31 to 4.55]) nor major bleeding (1.02 [0.42 to 2.47],  $p = 0.97$ ).

It is worth noting the significant limitations of the analysis, which are acknowledged by the authors. Despite pooling from multiple studies, the sample size is still small and the number of events low. Nevertheless, these data are all we have at present and do not support use of NOAC over VKA for management of APS, which is perhaps a surprising finding in the context of those in non-valvular AF and VTE. This analysis comes after last year's publication of the INVICTUS trial, which included 4531 patients with valvular AF secondary to rheumatic heart disease, who were randomized to either rivaroxaban or VKA.4 After a mean follow up of 3.1 years, rivaroxaban was not non inferior to VKA in preventing the primary composite endpoint of stroke, systemic embolism, myocardial infarction, or death from vascular or unknown cause (proportional hazards ratio

1.25 [95% CI 1.10 to 1.41]) and indeed VKA demonstrated superiority ( $p < 0.001$ ). The authors carefully considered explanations for this but could not readily explain from their data, including detailed subgroup analysis, why VKA appeared to be superior in this setting in contrast to the opposite finding from multiple trials in patients with non-valvular AF.

Drugs such as rivaroxaban and apixaban target a single coagulation factor, Xa, whereas the chronic effect of VKA administration is broader, seeing levels of factors II, VII and IX as well as X reduced. It has been postulated that in the highest risk indications for OAC, single factor inhibition may not be adequate and this is one potential explanation for these findings. It is also worth noting that whilst the target INR in the studies of APS was generally 2.0 to 3.0, it was higher some patients e.g. with recurrent thrombosis. Conversely, the dose of rivaroxaban was 20 mg once daily (or 15 mg for renal adjustment) and apixaban 2.5 mg twice daily, which may leave some room for further intensification if stronger OAC effect is desired.

At present, therefore, the data **do not** support routine use of NOACs in APS or valvular AF and VKA should remain the OAC of choice in these conditions. Further work might explore if higher clinically available doses of NOAC or combinations of oral single factor inhibitors provide better antithrombotic protection in these particularly prothrombotic settings.

Citation: <https://doi.org/10.1016/j.jacc.2022.10.008>



**Walmart Shoppers:**  
**You can make a difference!**

Did you know that every time you shop on Walmart.com, you can round up your change and donate it to **APS FOUNDATION OF AMERICA INC?** Learn how small acts can lead to big impact at WalmartSparkGood

<https://www.walmart.com/nonprofits/05803d83-09d1-43d8-a6c7-964a0c6655d4/profile>

Phone: 608-782-2626  
E-mail: [apsfa@apsfa.org](mailto:apsfa@apsfa.org)  
Website: <https://apsfa.org>  
Facebook: [www.facebook.com/APSFA](https://www.facebook.com/APSFA)

FIRST  
CLASS  
STAMP



## 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.



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>**

