APS Foundation of America

# ANTIPHOSPHO...WHAT?

APS Foundation of America, Inc.

## Exciting Updates: DARE-APS

**By Jason Knight, MD, University of Michigan**

Since 2019, Drs. Knight, Madison, and the APS Research Labs have been working with Dr. Doruk Erkan and his team at the Hospital for Special Surgery, APS ACTION, and researchers at both the National Institutes of Health and the Immune Tolerance Network to develop a first-of-its-kind clinical trial for individuals living with APS. We are thrilled to share that the trial is active, and we are currently recruiting patients to participate!

dare – APS

DARE-APS Study: We all know that safer and more effective treatments for APS are needed. In this research study, we will learn about the safety of the drug Darzalex® (daratumumab) in patients with APS. We will also learn whether it reduces levels of the antiphospholipid antibodies that cause APS.

Interested in advancing a potential new therapy for Antiphospholipid Syndrome (APS)? Click here to learn more about DARE-APS, a study that examines the impact of a medication called daratumumab in individuals with APS.

**Eligibility:** You may be eligible to participate in DARE-APS if you:

- Are between the ages of 18 and 70
- Have a diagnosis of APS
- Have triple positivity with positive testing for lupus anticoagulant, anticardiolipin IgG antibodies, and anti-beta-2 glycoprotein I IgG antibodies
- Do not have lupus

About the Study Drug: Daratumumab is an antibody that targets a protein called CD38, which is found on the surface of the immune cells that produce antiphospholipid antibodies (plasma cells). In APS, daratumumab may work by eliminating these antiphospholipid antibody-producing cells, thereby reducing damage to the body caused by antiphospholipid antibodies.

Participating in DARE-APS: This occurs in two phases. During the treatment phase, participants receive 8 weekly intravenous (IV) doses of daratumumab. The post-treatment follow-up phase lasts an additional 10 months, during which 6 monitoring visits occur.

**Updates:** So far, four individuals have participated at U-M. We are looking for someone to participate in the next dosing phase! We can only enroll one participant at a time, but we will keep a waitlist if there are many interested individuals. If you think that you may be eligible and would like to be considered for participation, you may contact us at csarosh@med.umich.edu or 734-647-5644.

To learn more, visit the DARE-APS website and find the study locations across the United States.

## 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 requesting 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 is still at a halt so it has left many project hurting including out bank account. 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 have done as many microgrants as we can but we are now in need of money.*

*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 not, AI will do 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 far as as the format of the newsletter, that probably will be changing thanks to Microsoft dumping Publisher. This will probably be the last formal newsletter. I have new medical issues that do not allow me to see very well and working endlessly on Canva to produce a newsletter in this format will not be conducive to my health.*

*Speaking of my health, I was diagnosed with a progressive neuromuscular disorder called Myasthenia Gravis. It effects both my eyes with double vision, my muscles, my ability to eat and drink, my voice and speech, it makes my eyes droop, walk and can effect my breathing. (Remember, when I say, it may not always be APS.) I am on infusions (the selection oddly including many that are for Lupus), a way stronger immunosuppressant and a special drug for my muscles I have to take 4 times a day on top of the pharmacy I was already taking. Medical burn out **IS** real.*

*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. You can also check out our Amazon Shop. We are adding new items to that regularly as I stumble on useful things for our community.*

*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. However, we are now on TikTok and starting to gain some traction and getting interaction with other APS patients and doctors there.*

*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*

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***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.**

## Jackie's APS Journey
## By Jackie Wright

I was first told I had APS when I was 19 years old. I had just given birth to my 27-week stillborn son, Xander, a month prior. I was told APS was the cause; my placenta was covered in hemorrhages, clots, scar tissue, and there was a blood clot in the umbilical cord. Maternal fetal medicine said my pregnancies are now high risk, but they could give me a healthy baby with treatment.

I had my second child at 22, and my little girl was stillborn at 28 weeks due to APS. I took baby aspirin and Lovenox during my entire pregnancy, but not enough. Doctors said they were sorry, and we can do more next time.

My doctor took me off the blood thinners and put me on the pill so I wouldn't get pregnant again. I was done with trying. I was traumatized at that point.

I then suffered several TIA's over the next month from the APS and estrogen-based birth control my doctor had put me on. I was told I have APS all the time, and I had to take warfarin for the rest of my life because my APS tests were strongly positive on all 3 tests.
I had to stop the birth control and start warfarin; my whole life flipped upside down at 22 years old.

I was blessed with a miracle two months later: I was pregnant again. I got smarter, saw better doctors, and received the best treatment available in my state. My pregnancy was insane, so many medications, tests, appointments, ultrasounds, half a million dollars later, at 32 weeks, I gave birth to a healthy 3-pound 12-ounce baby girl. My rainbow baby, my miracle. I had my tubes tied during my c-section. I knew I had my miracle, and I couldn't risk my life to have any more.

It's been 10 years since then. I have had multiple occasions of INR interactions, causing blood to be too thin or too thick. I've had internal bleeding several times, but knock on wood, I haven't had a blood clot since I started warfarin 12 years ago. I have learned to be my own advocate, and sometimes I know more than my own doctors. But I will always fight for my life!

I am 34 now, and I have several other health problems: fibromyalgia, Sjogren's syndrome, MCAS, scoliosis, osteoarthritis, anxiety, depression, tachycardia, mixed headache syndrome, Raynaud's syndrome, and endometriosis. I'm still trying to live my best life and enjoy each day to the fullest.

APS is a devastating disease that is very misunderstood. We must advocate for ourselves and give ourselves grace.

# Tree of Life Fundraiser

Welcome to the Tree of Life Fundraiser!

Join us in growing something significant. By purchasing awareness ribbons, flowers, bees, and dragonflies for our beautiful Tree of Life and its vibrant Spring scene, you're directly supporting the APS Foundation of America in its mission to raise awareness, provide education, and fund research for Antiphospholipid Syndrome (APS).

Every ribbon, bloom, and detail added to this scene represents a step toward hope, healing, and community. Together, let's nurture a brighter future, one piece at a time.

**How it works:** Donations are made using the buttons below the tree. There is an item that corresponds to different donation amounts. Once you have donated, the item you picked will be added to the tree. The Tree of Life starts bare, but as the Month of June progresses, the tree will be decorated with your generous donations!! At the fundraiser's end, our tree is beautifully decorated with ribbons, and our Spring scene is decorated with flowers, bees, and dragonflies.

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

All donations to the giving tree are 100% tax-deductible.

Please scroll past the tree to find the ornament selections and donate buttons. Or click here to jump there.

Thank you for considering the APSFA for your Spring or Summer donations and your continued support!

# APS & Contraception

## By Jackie Madison, MD & Angela Weyand, MD

Today, we'll be reviewing how the choice of contraceptive therapy is a little more complex in patients with APS. One important aspect of APS treatment is ensuring our patients don't have other risk factors for clots, or, if they do, finding ways to reduce those risks. One of these potential risk factors is the use of systemic estrogen therapy, most commonly in oral contraceptive pills (OCPs). There are other times estrogen treatment is considered, especially in menopause, and I hope to address this topic in a future post, but today's post is all about hormonal and other contraceptive choices. This post is co-written by our friend and colleague in Pediatric Hematology, Dr. Angela Weyand, who, in addition to treating and studying APS, also has a particular interest in women's health.

### Oral Contraceptive Pills

Hormone therapies like OCPs are used for a variety of reasons, including heavy menstrual periods, acne, and contraception. The problem for patients with antiphospholipid antibodies (even those without a prior clot) is that the combined OCPs, which contain estrogen (called combined OCPs because they contain both estrogen and progesterone), lead to a greater risk of blood clots. In fact, we have a number of patients who weren't diagnosed with APS until after they were put on an OCP and then developed a blood clot! Only then were the antiphospholipid antibodies identified, leading to their APS diagnosis.

So, what OCPs can be used when you have APS? There are OCPs that contain progesterone only, and these are relatively safe for patients with antiphospholipid antibodies1. The progesterone-only OCPs are also sometimes called the "Mini Pill," and they are even available over the counter. One particular aspect of their use is that they work best when taken at exactly the same time every day (set that phone alarm when the dose is due!). The Mini Pill is considered effective, just like other OCP's, but with typical (not perfect) use, there is a 6-9% risk of pregnancy each year2.

### Other Contraceptives to Avoid in APS

There are other contraceptives that are effective (6-9% risk of pregnancy per year) but best avoided in people with antiphospholipid antibodies. These include depot medroxyprogesterone acetate (aka DMPA or DepoProvera, injections every 3 months), vaginal rings (such as NuvaRing), and transdermal patches (applied to the skin). The ring and the patch contain estrogen at high enough doses that they should be avoided in APS. Depo (DMPA) is a progestin-only contraceptive, but in some studies, users had an increased risk of clotting (perhaps double)3,4. These studies could not perfectly capture whether there is a definite risk or exactly how high it may be, or if there is a risk specifically related to antiphospholipid antibodies; perhaps the only people enrolling were already avoiding estrogen because they already had an increased clotting risk. Still, because of the finding, we advise our patients with APS or other risk factors for clots to avoid DMPA injections.

### Highly Effective Contraceptive Options in APS

There are several options that are considered highly effective (<1% pregnancy risk each year) for contraception, meaning they are more effective than the Mini Pill. There are multiple types of IUDs (intrauterine devices), and all are considered safe for patients with APS1. IUDs may be particularly useful to women who are not planning on pregnancy in the near future because they last 3-10 years before needing replacement, depending on the specific device chosen. The hormonal (levonorgestrel) IUDs have the lowest rates of pregnancy (0.07% per year), and the hormone included is a tiny amount of progestin, not estrogen. Some example brand names include Mirena and Kyleena. Copper IUDs also have very low rates of pregnancy (0.63% per year) and contain no hormone. The downside is that for women on anticoagulation, they can experience heavy menstrual bleeding on copper IUDs. Cyclic menstrual bleeding often stops in users of hormonal IUDs. Hormonal IUDs can also be used to reduce dysmenorrhea and endometriosis-related pelvic pain.

Another highly effective option is the implant (for example, Nexplanon), which contains only progestin. An implant looks like a tiny plastic rod that is placed under the skin and lasts for 5 years before it is replaced. Are there clotting risks, perhaps similar to Depo? Although the American College of Rheumatology in its last reproductive health guidelines in 2020 advised caution because there were not yet a lot of studies on the topic, additional studies have been done since then, and the 2024 conclusion from the CDC is that the progestin implants are a reasonable choice for women with a history of clotting, similar to progestin-only pills5. One other downside for women on anticoagulation, though, is that some women can have irregular menstrual bleeding.

# APS & Contraception—Continued

### Less effective, but low-risk contraception choices in APS

There are other contraceptive options which pose no clotting risk, but they are not nearly as effective as the options above:

| Contraceptive Choices in Patients with Antiphospholipid Antibodies | Safety grade from the CDC | Effectiveness Category |
|---|---|---|
| Copper IUD | 1 | Highly Effective |
| Hormonal IUD | 2 | Highly Effective |
| Implant | 2 | Highly Effective |
| Progestin-only pill | 2 | Highly Effective |
| DMPA (Depot)—avoid | 3 | Effective |
| Combined OCP—avoid | 4 | Effective |
| Condom, diaphragm, sponge, cervical cap, spermicide, fertility awareness | Not graded; no known risk for thrombosis | Ineffective |

Safety grading: 1=no restriction, 2=advantages outweigh risks, 3=risks outweigh advantages, 4=unacceptable health risk. Effectiveness category: highly effective indicates <1% pregnant each year, effective indicates 6-9% pregnant each year, and ineffective indicates 10-25% pregnant each year.

condoms, diaphragms, sponges, cervical caps, spermicide, and fertility awareness (calendar methods). In these options, there is a 10-25% risk of pregnancy per year with typical use.

### Emergency Contraception

Emergency contraception (which prevents ovulation, thus preventing pregnancy) is also safe for women with APS. There are 2 oral emergency contraceptive methods available in the United States (ulipristal acetate and levonorgestrel, which is available over the counter as Plan B), and neither contains estrogen. IUD placement can also work as emergency contraception.

### What is the best choice for me?

The best choice for an individual is highly personal and depends on preferences and specific medical history. Talk about your options with your rheumatologist, hematologist, obstetrician/gynecologist, and/or primary care physician. Because pregnancy is high-risk for patients with APS, the choice of contraception is very important. There are multiple choices, but you do need to be thoughtful about which are safe and which might be best for you.

**Additional information:** This linked handout was made specifically for lupus patients, but many of the same principles apply to APS, and it notes particular areas that apply to people with antiphospholipid antibody positivity. The first page addresses pregnancy planning, and the second goes through birth control options. Check it out!


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5. https://www.cdc.gov/contraception/media/pdfs/2024/07/us-mec-summary-chart-color-508.pdf


### In This Story


Jaqueline Madison

Jacqueline Madison, MD

Co-author: Dr. Angela Weyand, Clinical Associate Professor of Pediatrics, Pediatric Hematology/Oncology. Dr. Weyand is a co-chair of the International Society for Thrombosis and Haemostasis (ISTH) Scientific and Standardization Committee on Women's Health, a member of the ISTH guidance and guidelines committee, and a section lead for the Lancet Haematology Commission on Women's Health.

# Sophia' Story

## By Sopia Love

Hi everyone, my name is Sophia Lowe and I had my first stroke at 33.

I wanted to share a bit about what I've been going through, health-wise, over the past few years. It's been quite a journey, and I've learned a lot about my body – and my resilience!

It all started back in September 2024. My right arm just suddenly went weak and dropped for a few minutes. It was weird, but it went away quickly, so I didn't think much of it at the time. Then, towards the end of 2024 and into 2025, I started losing a *lot* of weight without trying – I dropped from 178 pounds to 143! On top of that, I had constant nerve pain and kept breaking out in hives. It was all super confusing and concerning.

Things really came to a head on June 6, 2025. I was in the shower when my right arm went completely weak again, and I couldn't even hold things. To make it worse, I suddenly couldn't speak properly – my words were all jumbled. It was terrifying, and I ended up in the hospital on June 7th.

After a bunch of scans and tests, they confirmed I'd had a stroke. But that wasn't all! While I was there, they also found some pretty big kidney stones, diagnosed me with Chronic Kidney Disease, and discovered I had some internal bleeding. Talk about a triple whammy! About a week into my hospital stay, I even had a mini-stroke (a TIA) while being taken for a CT scan, which landed me in the ICU for a week of really close monitoring.

> I'm just incredibly grateful to still be here and keep pushing forward!

I was in the hospital for a good three weeks, from June 7th to June 27th, and then went straight to rehab until July 4th. I worked really hard there to get some of my strength and movement back. I finally got home on July 4th, but my homecoming was short-lived. Just three days later, on July 7th, I had *another* TIA and was back in the emergency room via ambulance.

After that, I saw a rheumatologist who eventually figured out what was really going on: Antiphospholipid Syndrome (APS). This diagnosis was a huge relief because it finally explained *everything* – even a miscarriage I had back in 2021. It showed that all these weird symptoms were connected to one underlying condition.

Then, on December 7th, I had yet *another* TIA in a store parking lot. That one happened because I had to temporarily stop my blood thinners for a kidney surgery I had scheduled on December 9th.

So, now I'm living with a higher risk of more TIAs and actively managing all these chronic conditions. It's definitely been a huge challenge, especially with my memory not being what it used to be and my right arm still feeling weak. But honestly, I'm just incredibly grateful to still be here and keep pushing forward!

# University of Michigan & APSFA Webinar: June 9th

*We cordially invite you to join our special webinar with the University of Michigan on June 9th from 6:00 PM–7:30 PM ET.*

Join us for an evening of Hot Topic Sessions and Questions & Answers to learn, stay informed, and get support for the APS community.

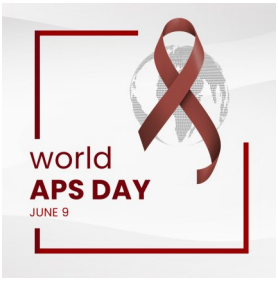
We kindly request that you register using the following link: https://umichumhs.qualtrics.com/jfe/form/SV_eKaKFeiEhFJBbzE

Registration closes on June 1st, and the event will be recorded for replay.

The full agenda can be found here: https://apsfa.org/new/wp-content/uploads/2026/05/U-of-M-APSFA-Webinar-June-9-2026-Agenda.pdf

Please submit your questions to: Tina@apsfa.org for the Questions & Answer Session.

We look forward to connecting with you and sharing this meaningful event together on World APS Day.




# Caregiver Burnout vs Compassion Fatigue: The Difference Reprinted from Trualta

Caregiving is a big responsibility that can be stressful, especially for family caregivers. Burnout is one possible result of prolonged stress. Compassion fatigue is also a serious potential consequence of caregiver stress.

In this article, we: describe caregiver burnout and compassion fatigue, list their symptoms, outline the differences between the, provide ideas for managing stress to avoid becoming burned out or fatigued.

### What Is Caregiver Burnout?

Caregiver burnout is a physical, mental, and emotional exhaustion resulting from prolonged stress experienced when providing care. Family caregivers are especially vulnerable to burnout for several reasons:

They're often unpaid and take on caregiving responsibilities while also working.

They don't always have help with home care and are often the primary caregiver.

Family caregivers are usually not trained for caregiving duties.

They are caring for a loved one. Watching them decline, especially in cases of dementia, can take a major emotional toll.

Signs & Symptoms of Caregiver Burnout

Anyone providing care is at risk for burnout. Family caregivers are often unprepared for the home care role and struggle to manage their responsibilities. This can lead to caregiver burnout. It's important to recognize the signs, so you can take steps to manage burnout and recover.

### Feeling Overwhelmed

Stress is normal in the caregiving role. You have a lot of responsibility, and the stakes are high. Your loved one's wellness and quality of life depend on your care. This can feel stressful and overwhelming at times.

It's not normal to feel stressed all the time when providing home care. Chronic stress is the underlying cause of caregiver burnout. If you feel constantly stressed and overwhelmed by your role, you could be headed for burnout.

### Exhaustion

You can recover and rebound from normal tiredness or fatigue with rest or sleep. Burnout is a state of deep exhaustion that does not get better with rest. It can be physical fatigue, but also emotional and mental exhaustion that you can't seem to get relief from.

### Poor Physical Health

Many caregivers struggle to take time for their own health and wellness. This can lead to poor physical health, getting sick more often, insomnia, and frequent issues like headaches or digestive problems. You should be concerned if you don't find time to rest, get enough sleep, eat well, or exercise.

### Mental Health Symptoms

According to research, caregivers suffer from depression at higher rates than the general public. They're vulnerable to other mental health symptoms as well, like anxiety. Leaving these unmanaged can easily lead to burnout. Caregivers with burnout often feel sad, hopeless, and overwhelmed.

Another troubling mental health symptom associated with burnout is anger. Burned-out caregivers often feel resentful and angry toward their care recipients. This can lead to outbursts and even abuse.

### Isolation & Withdrawal

Caregiving can be isolating, but if you find time to spend with family and friends, they can provide important support. Deepening isolation and withdrawal from normal activities are key characteristics of caregiver burnout.

### What Is Compassion Fatigue?

Compassion fatigue may occur with caregiver burnout, but it isn't the same. It is often referred to as the cost of caring, vicarious trauma, or secondary trauma. Compassion fatigue is rooted in empathy, the ability to understand and feel someone else's emotions. It's like putting yourself in someone else's shoes.

Empathy is a hallmark of a good caregiver, but it can also lead to compassion fatigue. Compassion fatigue is secondary traumatic stress and exhaustion. After being exposed to the traumatic experiences of another, such as the care recipient, the person with compassion fatigue begins to lose the ability to empathize, nurture, or provide care.

Caregivers are susceptible to compassion fatigue because they care for people who are sick or struggling. Anyone in a job that requires empathy and compassionate caregiving can be at risk: medical professionals, first responders, and veterinarians, for instance.

In caregiving, family caregivers may have a higher risk. They may feel the suffering of their loved ones more intensely than professional caregivers.

Signs & Symptoms of Compassion Fatigue

Compassion fatigue is different from, but related to, caregiver burnout. Both can be harmful to the caregiver and the care recipient. If you struggle to empathize, you can-

# Caregiver Burnout vs Compassion Fatigue: The Difference

not provide the best care. Your loved one may suffer more as a result.

**Know the signs of compassion fatigue before they arise:**

-You feel less caring, sympathetic, and empathetic toward your loved one. In deep compassion fatigue, you might feel no empathy at all.

-You feel detached from your care recipient. This feels like emotional numbness.

-Your approach to your caregiving tasks becomes more focused on just getting the job done and less on providing care or comfort. You struggle to function, think clearly, or complete your usual tasks.

-You get angry easily and are more irritable, cynical, and resentful. You may experience mood swings, outbursts, fear, sadness, and hopelessness.

-You become socially isolated and withdrawn, both from your care recipient and others.

-You feel deeply exhausted, physically, mentally, and emotionally, even with rest.

The last sign of compassion fatigue is similar to the experience of caregiver burnout. This type of exhaustion is different from the normal sensation of being tired or fatigued. It's not relieved by rest or sleep, and it can even make sleep more difficult.

**What Are The Key Differences?**

While compassion fatigue and caregiver burnout are very similar, there are important differences. Both result from providing care, but the real underlying causes are a little different, as are the timing and some of the symptoms.

**Compassion Fatigue Is More Emotional**

In both causes and symptoms, compassion fatigue is more emotional than physical, while burnout can be both.

Burnout results from ongoing stress from several sources: Being overworked, lack of caregiving training, inadequate sleep, and more.

Compassion fatigue is caused by emotional exposure to difficult situations. It arises after repeated exposure to someone else's suffering, trauma, or grief. While burnout is triggered by all kinds of stress, compassion fatigue's underlying cause is specifically secondary traumatic stress.

The symptoms of compassion fatigue are also more emotional.

Burnout causes both emotional pain and physical symptoms.

Compassion fatigue can result in physical symptoms because, like burnout, it involves a buildup of stress. Chronic compassion stress lowers immune function and can cause certain physical symptoms, like pain.

**Compassion Fatigue Can Occur Suddenly**

Caregiver burnout builds slowly, over time. It results from chronic stress. You might cope well initially, but as stressors pile up, you slowly get burned out. This is one reason burnout can be so harmful. It's not always easy to notice when it's happening.

Compassion fatigue can build slowly, but it also often occurs quickly. You might suddenly lose empathy after prolonged exposure to your care recipient's difficulties and suffering. Compassion fatigue can also arise quickly after one significant traumatic event.

**Burnout Does Not Cause Loss Of Empathy**

This is the most important difference between compassion fatigue and caregiver burnout. There is otherwise a lot of crossover, but this is the key characteristic of compassion fatigue.

Burnout can make it more difficult to provide good care, but you should still feel compassion, satisfaction, and a sense of wanting to care, even if you cannot. You still feel empathetic toward your loved one.

In compassion fatigue, you see this feeling of empathy decline and ultimately disappear. It feels like you no longer care. Both situations can make it difficult or impossible to provide care, but the underlying reasons are different.

Managing Burnout & Compassion Fatigue

If possible, it's best to recognize and address early signs of burnout and compassion fatigue. This helps you get back on track before entering a state of deep exhaustion and lack of empathy.

Whether you're experiencing burnout, compassion fatigue, or both, the most important thing you can do is take a break from care. Respite care is a service you should use early and often on your caregiving journey. Let someone else take over for short periods so that you can rest and manage your own health.

Support groups, used early and often, can also make a big difference to your mental health. A caregiver support group allows you to share difficult feelings in a safe space. Expressing these to people who understand your situation can be powerful for stress relief. You can also get advice and learn in support groups, making your role easier.

Burnout and compassion fatigue are serious mental health issues. If you cannot find relief, you may need professional support. A mental health professional can help you work through your feelings, find coping strategies for stress and depression, and find practical solutions to balancing your role as a caregiver and your own wellness.

Don't forget to check if you have free access to caregiver resources, support groups, and forums to help you cope.

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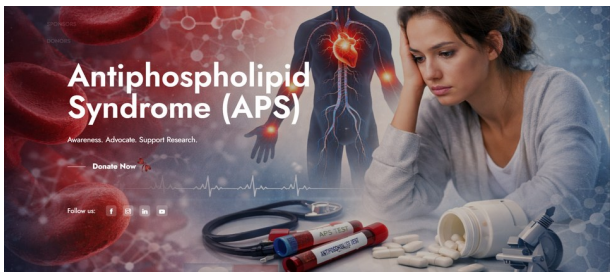
Stoewen, D. L. (2020). Moving from compassion fatigue to compassion resilience Part 4: Signs and consequences of compassion fatigue. Canadian Veterinary Journal, 61(11), 1207–1209.

National Council of Certified Dementia Practitioners. (n.d.). Caregiver burnout vs. compassion fatigue: What's the difference?

# New Website Launched—Check it Out!

We're thrilled to share that our brand-new website is live!

Our old site was stuck in the past with outdated templates, making it hard to keep things secure and implement the fantastic features we envisioned without breaking the bank. With this fresh design, we're all set for a smoother experience and can easily stay up to date.




We've also introduced features that boost our visibility on search engines, especially since we faced challenges when Tina is dealing with her latest autoimmune condition, a progressive neuromuscular disorder which requires her weekly infusions, chemo and medications 5 times a day.

While this upgrade came with some costs, we truly believe that quality, science-based information should always be prioritized. If you'd consider helping us cover some of these expenses, we would greatly appreciate it!

The great news is, this website is built for longevity, ready to serve you for the next decade.

**Check it out!** https://apsfa.org

# May is Stroke Awareness Month
# by Tina Pohlman

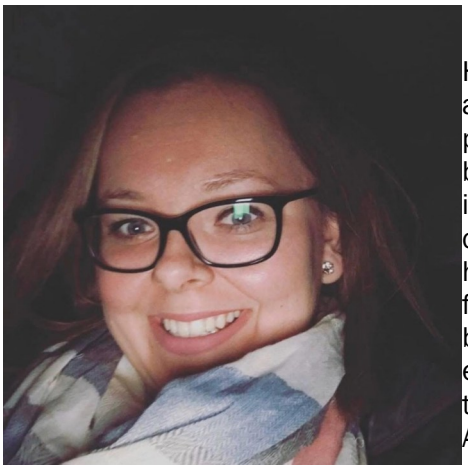
May is National Stroke Awareness Month, dedicated to educating the public on recognizing symptoms, understanding risks, and highlighting that 80% of strokes are preventable. Key initiatives emphasize acting B.E.F.A.S.T. (Balance, Eyes, Face drooping, Arm weakness, Speech difficulty, Time to call 911) because nearly 2 million brain cells die each minute a stroke goes untreated.

**Key Goals of Stroke Awareness Month:**
**Recognize Signs** (B.E. F.A.S.T.): Balance, Eyes, Face drooping, Arm weakness, Speech difficulty, and Time to call 911.
**Understand Risk Factors:** High blood pressure (hypertension), diabetes, and high cholesterol are major, controllable risk factors.


**Prevention Strategies:** The CDC notes that 80% of strokes are preventable through healthy lifestyle changes, such as eating a balanced diet, exercising for 150 minutes per week, and quitting smoking.
**Targeted Outreach:** Campaigns often target specific demographics, such as Black and Latina women aged 25-64, to monitor blood pressure.
**Support & Education:** Organizations like the American Heart Association offer resources and educational tools to help people understand, prevent, and recover from strokes.

**Citation:** heart.org

# My APS Journey
# By Jagoda Bach



Back story, my husband and I married in 2015 (July 11 (that number is significant!) to be exact) after being together for a few years. We wanted to start a family soon thereafter, as we both wanted a large family. I was praying for 2 boys, 2 girls; he just wanted a large family with at least 1 boy. In 2017, we found out I was pregnant with no complications. I developed preeclampsia at 35 weeks and ended up getting induced at 36 weeks 4 days. My original due date was August 4; our little angel came in the very early hours of July 11, 2018. Postpartum, I felt some sharp feelings in my shoulder through my chest, but I disregarded them and mentioned my concerns to the nurse. She said to let her know if the pain continues, all ended up resolving, and everything was fine. 2 weeks postpartum, the pain came back stronger than it was before. I had my 2-week postpartum appointment the next day, and I mentioned to the doctor that this was happening, but I wasn't sure if it was a postpartum situation or something more serious.

He sent me to radiology immediately, and they ended up finding a bilateral pulmonary embolism and DVT. I had 5 blood clots total (mind you, I had no idea what a PE was, let alone that it could be dangerous and that it could happen to a 31-year-old!). I was referred to a hematologist, started on blood thinners, and started doing several tests. I ended up coming back positive for 2 out of the 3 cardiolipins for APS 3x. I was on the lower end of the numbers, but still positive.

Our difficult journey was just ahead of us. In 2019, we had our first loss. It was very difficult to grasp the idea of loss and what our future would look like. We put it all in God's hands, though. Over the years, we just prayed for a miracle while I struggled with PTSD. Our daughter was getting older, constantly praying for a sister, and our hearts were breaking. We decided to give IVF or surrogacy a try. Because of the idea of injecting hormones into my body, my hematologist was recommending we not go that route; she was supportive but was erring on the side of caution. We went to see a high-risk doctor, and with the care of him, my hematologist, and OB/GYN, plus a whole village on our team, I started on Lovenox injections, baby aspirin, and we saw those 2 positive lines!

Throughout the pregnancy, we had several scares; my only wish was to get to viability, then after that, every week was a blessing. We received some scary news 3x confirming chromosome deficiencies, low fetal mass, you name it, we heard it. At our 20-week anatomy scan, my high-risk doctor said the baby girl looked perfect, but the Lovenox skewed all those results. Not to mention the number of hospital visits due to the baby's lack of movement!!

We made it to 30 weeks, then 32, then 35, and at 37, my high-risk doctor wanted to have me induced to eliminate the risk of what happened during my first pregnancy. What is so special and meaningful, our miracle rainbow was born on March 11, 2025, during blood clot awareness month, but also on the 11th, like our first daughter, and 11 being an angel number; she was and is definitely our angel babe.

I try daily not to let APS affect me, and I try daily not to let it control me. My anxiety spikes frequently when I have a weird feeling in my calf or a warm sensation in my arm, or a random sharp pain in my chest. Plenty of ER visits over the years confirmed everything was ok. My biggest fear, I never had those symptoms or side effects when I had my first PE and DVT in 2018. Currently, I have an annual ultrasound scheduled to make sure all is clear on the DVT side in my calves. It's very important to be proactive, and when you see or feel something, don't hesitate to get checked!!

Thank you for reading this far & thank you for allowing me to share my story!!

# What Has the APS Foundation of America, Inc Been Up Too?
## By Tina Pohlman


The past year has been very active for the APS Foundation of America, Inc. (APS). Some may believe we do not engage in research, fund research, or collaborate directly with researchers, but that is incorrect. It is all listed on Candid for full transparency, every year. Thank yous, receipts, etc are posted on our SmugMug as well from transparency.

In the last year alone, we supported three papers with microgrants: one by Andrew Song, who is at Mass Gen Brighman Women's got funding for small research studies. In a study with collaboration from Shruti Chaturvedi (Johns Hopkins) and Hanny Al-Samkari (Massachusetts General), we are interested in systematically assessing cognitive function, silent cerebral infarcts, patient-reported outcomes, and biomarker testing for complement activation. These are neurological entities that are not in the ACR/EULAR classification criteria but we believe confer significant unmet medical burden on patients with APS.

We also provided one to Behnood Bikdeli Antiphospholipid antibodies and cardiovascular thrombosis, Nature Reviews Cardiology, 2026.

Additionally, we donated to ICAPA to fund bursaries, enabling five individuals to use the money to attend the conference in Kyoto, Japan.

We also assisted Shruti Chaturvedi (Johns Hopkins), Andrew Song, (Mass Gen Brigham Women's), Sarah Rousel (Havard), and Tara Brady (Harvard) in creating a survey with that resulted in an accepted Poster Presentation and coauthorship for us at the ISTH Conference in Paris, held July 11-17, 2026.

This survey addressed cognitive challenges faced by patients with antiphospholipid syndrome and is expected to lead to numerous detailed studies, explaining why these issues occur despite normal MRIs.

Furthermore, we provided a matching grant to the University of Michigan for Jason Knight's Program, supported by their development program as we felt bad we have not contributed directly to their program and after talking to the new development team on how matching grants work we gave it a run and it worked quite well for the APS team at Ann Arbor.

We have also collaborated with the Mass General Brigham Women's Development Program. Both institutions have warmly welcomed us, and it has been a pleasure working with their teams. We look forward to supporting these and other teams in the future with microgrants, especially as the current economic climate remains challenging.

We are currently working on the Webinar with University of Michigan and project that we have a non-disclosure on at this time, sorry. But it is a very important topic.

We also have other big news to share that Christina Perri managed to do something I could not get done and get a HR Bill on the floor. HR 685 expressing testing for antiphospholipid syndrome as a standard prenatal screening and other purposes. See the press release here.

We had an opportunity to go to the Pediatric Rare Disease Summit at Boston Children's Hospital but we did not have the funding to get there and no one helped when we made a call for help. Our slot was taken even tho it is in October.

# Why You Should Donate to the APS Foundation of America for Awareness Month


Every June, Antiphospholipid Syndrome (APS) Awareness Month shines a light on a condition that is still too often overlooked—but for those living with it, APS is life-changing.

Donating to the APS Foundation of America, Inc. is one of the most meaningful ways to turn awareness into action.

### APS Is Serious—And Still Underrecognized

APS is an autoimmune disorder that causes the body to form dangerous blood clots. It can lead to:

- Stroke in young adults
- Deep vein thrombosis and pulmonary embolism
- Pregnancy complications, including recurrent miscarriage and stillbirth

Despite its severity, APS remains underdiagnosed, misunderstood, and underfunded.

### Your donation helps change that.

### You Help Drive Research Forward

Research into APS is still limited compared to many other conditions. That means:

- Fewer treatment options
- Slower progress toward better outcomes
- Limited awareness in the medical community

### Your support helps:

- Advance critical research initiatives
- Encourage collaboration among experts
- Move closer to safer, more effective treatments—and ultimately a cure

### You Expand Awareness That Saves Lives

Many people live with APS for years before receiving a diagnosis.

### Your donation helps:

- Educate healthcare providers
- Increase public awareness
- Promote early recognition

### Earlier diagnosis means fewer complications and saved lives

### You Support Patients and Families

Living with APS can be overwhelming—physically, emotionally, and financially.

### Your contribution helps provide:

- Trusted, accessible educational resources
- Patient support and community connection
- Hope for those navigating a complex condition

No one should have to face APS alone.

### You Help Build a Stronger Future

### When you donate, you're not just giving—you're investing in:

- Better care
- Stronger advocacy
- A more informed healthcare system
- A future where APS is recognized, treated effectively, and ultimately prevented

### The Impact Is Real

### Because of supporters like you:

- Awareness is growing
- Diagnoses are happening sooner
- Patients are finding support
- Research is gaining momentum

### This Awareness Month, Take Action

### Awareness is powerful—but action creates change.

- Donate
- Share
- Advocate

### Together, we can transform the future of APS.

### The Bottom Line

### Donating to the APS Foundation of America means:

- Lives are improved today
- Progress accelerates tomorrow
- Hope becomes real for thousands of families

## Together, We Change Lives

# How Social Security Determines Disability
## By the GWAAR Legal Services Team

If you've applied or thought about applying for Social Security disability benefits, you may have heard about the five-step process the Social Security Administration (SSA) uses to decide whether someone is disabled. Understanding how SSA makes disability determinations can help you understand why a claim was approved or denied. Read on to learn more about the process.

**Step 1: Are you working?**

Social Security first considers whether you are working and earning above a certain monthly amount. If you are earning too much, SSA usually decides that you are not disabled. If you are not working or earn below the limit, SSA will send the application to the Disability Determination Bureau (DDB) for the remaining steps.

**Step 2: Is your condition severe?**

Next, the DDB looks at your medical conditions. To qualify, your condition must be serious enough to limit your ability to do basic work activities, such as standing, lifting, remembering instructions, or concentrating. If the condition is not considered severe, the claim is denied. If it is severe, the DDB continues to Step 3.

**Step 3: Is your condition on SSA's list?**

SSA has a list of medical conditions that are considered automatically disabling. If your condition meets or equals one of these listings, you are determined to be disabled. If it does not, the DDB will move on to the next step.

**Step 4: Can you do your past work?**

At this step, the DDB reviews the jobs you have done in the last 15 years. They decide whether you can still do any of that work based on your medical limits. If you can still perform your past work, your claim is denied. If you cannot, the DDB goes to the final step.

**Step 5: Can you do any other work?**

Finally, the DDB assesses whether you can do any other type of work in the national economy. They consider your age, education, work experience, and physical or mental limitations. If SSA decides you cannot adjust to other work, you are found disabled. If they decide you can work, the claim is denied.

**For more information, please see:**

https://www.ssa.gov/benefits/disability/qualify.html or talk to a disability attorney.

# Shopify Gift Shoppe

**Written by Carla Moore**

We would like to notify you to our Shopify Gift Shoppe will close July 1st. Not to worry we moved to WooCommerce at Shop. It is now built in to our website.

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 PS Foundation of America, Inc.

**Visit our shoppe at:**

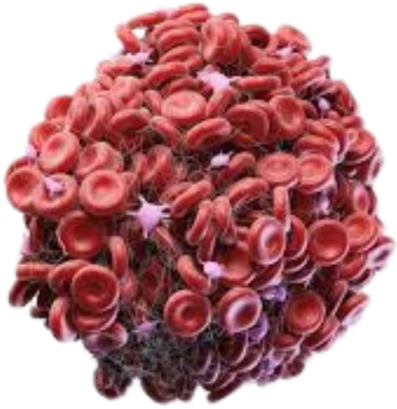
https://apsfa.org/shop

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

## A Summary of Understanding APS Clinical Phenotypes with the guidance of antiphospholipid antibody-relate pathogenic mechanisms

**Written By: Doruk Erkan, MD, et al - APS ACTION**

A recent review article by Sevim E, Erton ZB, and Erkan D, published in Current Opinion in Immunology, June 2026, entitled *Understanding antiphospholipid syndrome clinical phenotypes with the guidance of antiphospholipid antibody-related pathogenic mechanisms* summarizes how antiphospholipid antibodies (aPL) can contribute to the wide range of clinical problems seen in antiphospholipid syndrome (APS).



The authors describe APS as a condition in which the immune system, blood vessels, platelets (tiny blood cells involved in clotting), complement system (a part of the immune system that amplifies inflammation), and excessive clotting interact to create an inflammatory and clot-prone environment.

Although many APS complications share these common mechanisms, the review emphasizes that different APS features may develop through somewhat different or nuanced pathways. This matters because understanding the dominant mechanism in each patient may eventually help doctors identify which type of APS a patient has and choose more targeted treatments.

For instance, in aPL-related small blood vessel disease, repeated tiny clots and ongoing vessel wall injury can lead to scarring and narrowing of small vessels, potentially affecting organs such as the kidneys, skin, lungs, heart, or adrenal glands, causing damage over time. Additionally, pregnancy complications in APS are not caused only by blood clots in the placenta. Antiphospholipid antibodies can also directly affect placental cells and disturb the balance of proteins that support healthy blood vessel growth, which may contribute to miscarriage, fetal loss, or severe preeclampsia.

And in patients with low platelet counts, aPL appear to both directly activate and consume platelets while also engaging the immune system to destroy them, a combination that raises the risk of bleeding as well as, paradoxically, further clotting.

At the most severe end of the spectrum, catastrophic APS (CAPS) occurs when these shared mechanisms suddenly become active across multiple organs, creating a rapidly escalating, life-threatening emergency. The review also points to a growing number of targeted therapies being studied beyond standard blood thinners, including drugs that block complement activation, dampen immune cell activity, or interrupt specific signaling pathways driving vessel damage. One of the key messages is that APS is not a one-size-fits-all condition: better understanding the mechanisms driving the disease in each patient may increasingly guide more personalized and effective treatment in the future.

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APS Foundation of America

Antiphospho.....what?!?!

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# 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 or search "apsfa" on the general website.**