



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!



New classification criteria for Antiphospholipid Syndrome (APS) Reviewed by Megan Craig, M.Sc.

APS is a systemic autoimmune disease associated with persistent antiphospholipid antibodies (aPL). It can cause thrombosis and pregnancy complications as well as non-thrombotic manifestations such as cardiac valve disease.

Classification is important to help identify people to take part in research and ensures that similar disease states are included and compared in trials. This is different to tools that help clinicians make a diagnosis.

The APS classification criteria were last revised in 2006, but since then understanding of the disease has evolved. EULAR and ACR worked together to develop a new APS classification system based on modern disease understanding. The intention was that the new tool would also allow individual criteria and different risk profiles to be weighted and demonstrate excellent operating characteristics with the highest possible specificity. Four key phases in the development of the criteria were followed: generation; item reduction; definition, further reduction, and weighting, threshold identification; and finally, validation.

After reductions and revisions, the updated classification specifies an entry criterion of at least one positive aPL test within 3 years of identification of an aPL-associated clinical criterion. This is followed by a set of weighted criteria, each scoring 1-7 points. The criteria are clustered into six clinical domains and two laboratory domains. The clinical domains are macrovascular venous thromboembolism,

macrovascular arterial thrombosis, microvascular, obstetric, cardiac valve, and hematology. The laboratory domains include assays and antibody tests to increase the specificity of the criteria. Patients scoring at least 3 points from each of the clinical and laboratory domains are classified as having APS.

The new classification criteria were tested in potential APS cases, with results showing good sensitivity and specificity. In fact, specificity for the new classification system was 99%, compared to 86% achieved with the original 2006 criteria. This is important, because classification criteria are based on standardized and stringent definitions to ensure consistency in clinical trials, and so very high specificity is required, even at the cost of sensitivity.

EULAR hopes that these new classification criteria will support high-quality, risk-stratified epidemiologic studies and clinical trials in APS, and ultimately lead to improved patient care and management recommendations.

So what does this mean for you? Easier and more precise way diagnose new cases going forward.

Source: European Alliance of Associations for Rheumatology

Journal reference: Barbhaiya, M., et al. (2023) ACR/EULAR antiphospholipid syndrome classification criteria. *Annals of the Rheumatic Diseases*. doi.org/10.1136/ard-2023-224609.

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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!

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Letter from the President



November is here and we are first snow our first snow in Wisconsin. I broke my ankle last year so winter is not my most favorite time of the year.

A lot has happened since our last newsletter. It is hard for me to do this most of this alone while having Lupus and APS plus I have too many irons

in the fire. If you want to volunteer, please message me at apsfa@apsfa.org.

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.

Stago Diagnostics made a video with one of our volunteers on APS. Watch it here: <https://youtu.be/B6qPRciQADs> We also did a men's round table with Stago—sorry no link. They did a great job! We also need a info video for our website, if anyone would like to make a professional one.

Jason Knight, MD and I did a [beyond biotech](#) podcast for APS Awareness Month. We think it turned out ok.

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

As a reminder are on [Walmart's SparkGood](#). You can donate money to the APSFA just by shopping. Just set the APSFA to your designated charity. We are also with Target and Front Door. Sadly, Amazon discontinued their program. :(

We encourage you to follow us on [Facebook](#), [Instagram](#) and [Twitter](#) to get the **latest** APS news. Twitter has a great exchange with medical professionals interested in APS.

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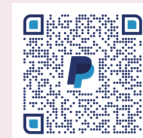
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If you have a medical emergency, please call your doctor or 911 immediately.

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Why We Need to Talk About APS: A Little-Known Autoimmune Condition

By: Millie Fuller

Autoimmune illnesses pose a challenge for clinicians as there's often no apparent root cause, and multiple conditions can present with similar symptoms. Patients may report generally feeling unwell, having pain, and frequent headaches, making diagnosis difficult and increasing the likelihood of misdiagnosis.

The healthcare system can feel like a waiting room that you never leave. You visit various doctors, only to receive incorrect diagnoses or have your concerns dismissed entirely. This isn't only frustrating for the patient, but it's also expensive for the system.

Antiphospholipid syndrome (APS) is a good example of this 'revolving door' because it can take 5 years to receive a diagnosis.

I'd never heard of APS, so it was a surprise when I was told I had it. The condition doesn't get much attention or media coverage like the [more well-known rare disorders](#) of haemophilia or cystic fibrosis. But, despite being bewildered by the diagnosis, I'm fortunate to have received one at all.

Many people would argue that the issue lies in getting a diagnosis, and they'd be right. It's the starting point for receiving treatment. For many, finding out can actually be a positive experience.

Imagine being doubted by the doctors, your colleagues, family, and friends. Your exhaustion is put down to a consequence of a late night, your muscle aches as a result of a sedentary lifestyle, and your memory lapses as a figment of your imagination. A diagnosis provides validation. It's a powerful thing called proof.

Table showing different organ systems and how APS may affect them

Organ System	Selected Antiphospholipid Syndrome-related Clinical Problems
Nervous system	Stroke, transient ischemic attacks ¹ , memory problems
Kidney	High blood pressure, chronic kidney disease, protein in the urine
Heart	Myocardial infarctions, vegetations ² on valves, thickened and leaky valves
Blood	Anemia, low platelet counts
Skin	Livedo ³ , skin ulcerations
Blood vessels	Deep venous thrombosis ⁴ (DVT)
Lungs	Pulmonary embolism ⁵ , pulmonary hypertension ⁶
Pregnancy	Miscarriages, premature births, fetal growth restriction

[Source](#)

There's also an argument that the rarity is debatable. This is because of misdiagnosis – realistically, the

data is only presenting us with a small fraction of the actual cases. The likelihood is that there's more that are living with the condition without knowing.

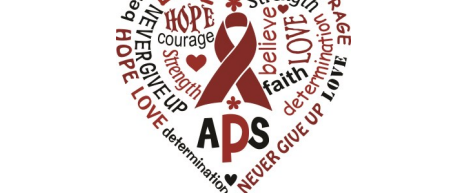
However, those with a rare disorder aren't alone. Despite the uniqueness of our disorders, many of us have the same experiences, thoughts, and feelings. Some conditions are more visible than others, but they all come with a burden to bear.

However, what if a diagnosis can offer no solution? This is the case with APS, for which there's only palliative care available [and no cure](#).

Conditions defined as rare affect a very small proportion (up to 1 in 2000 people). Consequently, the target market isn't considered attractive from a business standpoint. Pharmaceutical companies have little or no incentive to invest in research for these illnesses, as they're far less prevalent than common conditions.

The result is that rare diseases [don't receive much attention](#). Furthermore, awareness campaigns often center on the pain and suffering of patients. This puts a burden on each, forcing them to prove their need and worthiness. Despite my awareness of this fact, I'm not immune to it. Thus, I'll make the case for APS.

APS is a rare autoimmune disorder that can cause blood clots to form. Thrombosis' are most common in the legs (Deep Vein Thrombosis) but they can form elsewhere (in my case, the brain). It's often only suspected after multiple miscarriages, blood clots, or a [catastrophic antiphospholipid syndrome](#) event from which only 50% survive. Because it involves the blood, APS can cause a wide range of symptoms – some specific and some less so.





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](#). 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 12/31/2023) are 100% tax deductible. Donation over \$200 through PayPal will get an APS tote bag from our CafePress Store valued at \$18.00 USD while supplies last.



Our last tree.





Understanding Autoimmune Diseases When Your Body Turns Against You

By: NIH News in Health

Your body's disease defense system, called the immune system, goes to battle every day. It helps keep you healthy by fighting off viruses and bacteria that sneak into your body. But sometimes, your immune system makes mistakes. If it sees your body's healthy cells as a threat, it may attack them. This can cause an autoimmune disorder.

There are many different autoimmune diseases. Some involve only one type of tissue. For example, in a disease called vasculitis, your immune system attacks your blood vessels. Other autoimmune diseases involve many different parts of the body.

Lupus, for example, can damage the skin, heart, lungs, and more.

Most autoimmune diseases cause inflammation. But the symptoms they cause depend on the body parts affected. You can have pain in your joints or muscles. Or you may experience skin rashes, fevers, or fatigue.

Researchers still don't know what causes most autoimmune diseases. But they've made progress in understanding what puts you at risk and figuring out ways to diagnose and treat them.

What Are the Triggers?

Some autoimmune diseases are rare, but others are fairly common. About 1% of people in the U.S. have rheumatoid arthritis, explains Dr. Mariana Kaplan, an NIH specialist in autoimmune diseases. Rheumatoid arthritis damages the joints.

Certain genes put you at higher risk for developing an autoimmune disorder. But genes alone aren't usually enough, says Dr. Peter Grayson, an NIH expert on vasculitis.

His team recently found a single gene change that can cause vasculitis in older men.

Most people who carry genes linked with autoimmune diseases still won't develop one. Usually, one or more triggers are needed to set off the immune system.

Different things in your environment can serve as triggers, explains Dr. Andrew Mammen, an NIH expert on muscle diseases. His team studies myositis, a disease in which immune cells attack the muscles.

Too much sun exposure can trigger a type of myositis in people who have certain genetic risk factors, Mammen explains. But, he says, most people need other triggers as well to develop the condition. What they are aren't always clear.

Certain viruses can also jump-start an autoimmune attack. A recent NIH-funded study found that a virus called Epstein-Barr may trigger some cases of multiple sclerosis, or MS. MS is an autoimmune disease that damages the nerves.

Other risk factors can be your age, sex, smoking history, and weight. Many autoimmune diseases are also more common in women than men.

Getting a Diagnosis

A diagnosis of an autoimmune disease can take time, says Grayson. Especially if it's one that affects many parts of the body.

People often turn to different doctors for different symptoms. "If you're seeing, for example, an eye doctor, a skin doctor, and a lung doctor separately, they may not see that your symptoms are connected," says Grayson.

Symptoms of autoimmune diseases can also mimic those of many other conditions. "For example, we call lupus 'the great imitator,' because it can look like many other diseases," Kaplan says.

Talk with your health care provider if you're having muscle, bone, or joint pain that's not related to an injury. Or if you've had pain in multiple areas or for long periods of time. They may refer you to a rheumatologist. This is a doctor who specializes in diseases that cause inflammation.

Your doctor may use blood tests to look for antibodies that are attacking your own tissues. These are called autoantibodies. But having them in your blood isn't enough to be diagnosed with an autoimmune disease. Many people have them in their blood but don't get sick, Kaplan explains.

Imaging technologies can be used to look for signs of an autoimmune disorder, too. X-rays can show joint issues. MRIs can reveal damage deep in the body.

Researchers are trying to find new ways to use imaging to help diagnose or monitor autoimmune disease. Grayson's lab is testing whether PET scans can find hidden inflammation in the blood vessels of people with vasculitis.

Tamping Down the Attack

There are no cures for autoimmune disorders yet. But researchers have made progress in managing symptoms.

Drugs called corticosteroids are often the first treatment for an autoimmune disease. "They work quickly, and they're effective," Mammen says.

But steroids suppress your entire immune system. So they can have serious side effects. These include high blood pressure, bone loss, and weight gain.

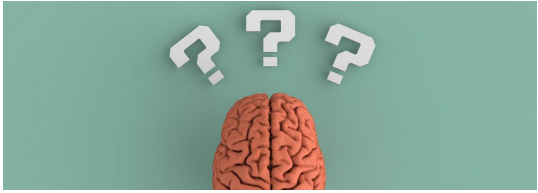


(Continued on page 8)



Is It a Ministroke? Know the Warning Signs of a TIA

Written by: Rachel Nania, AARP



In her mind she was talking — relaying to her hairstylist stories from her recent trip to Rome. But as Beth Bonness

looked at herself in the mirror, dye still in her hair, she could see her mouth wasn't moving. That's weird, she thought.

Snowflake-like lights appeared to the side of her left eye, and her right hand curled into a claw. Her stylist — asking Bonness if she was OK, if she needed help — sounded like she was underwater.

"And there was pressure, but no pain," says Bonness, of Portland, Oregon.

The whole thing lasted a few minutes — maybe four, she recalls. So Bonness, then 49, finished up her hair appointment, met her family for dinner at a nearby restaurant, then went home and filled her husband in on the strange events of the afternoon.

Soon after, Bonness was in the emergency room getting checked out. It was there she learned, blood pressure sky high, she likely had a transient ischemic attack, or TIA, which happens when blood flow to the brain is temporarily blocked. Roughly 240,000 Americans a year have a TIA, sometimes called a ministroke, according to the American Stroke Association. And though they can occur at any age, they're most common among adults 55 and older.

Bonness went home with blood pressure medication and a plan to take it easy for a few days.

Knowing when to seek help

It's not uncommon for symptoms such as the ones Bonness experienced to be brushed aside, says Hardik P. Amin, M.D., associate professor of neurology and medical stroke director at Yale New Haven Hospital St. Raphael Campus in Connecticut. A big reason: When it comes to a TIA, there's no pain involved.

"Usually if there's a pain component, that's going to send folks running to the hospital," Amin says. "Here, it's more like a loss of ability to do something." And that loss of ability quickly resolves, often within a few minutes.

A short-lived weakness or numbness in the arm? "Sometimes patients just think, Oh, I just slept on it funny. I'll try to shake it off or just kind of work through it and see if it just gets better on its own," Amin says.

Bonness, who was a busy working mother, admits that when her TIA was happening, "there was a soft little part" of her that thought it could be stroke related. But with everything going on in her life, she

says, "there wasn't a lot of air space for the quiet warning signs to percolate."

Doctors, however, say it's important not to overlook TIA symptoms. In fact, they require immediate medical attention, a new scientific statement from the American Heart Association (AHA) says. Diagnosing a TIA and understanding its root cause can help prevent a full-blown stroke, which can cause lasting brain damage and long-term disability — even death.

"TIAs can be a harbinger of something really bad," says Arif Jivan, M.D., an interventional cardiologist at Northwestern Medicine Lake Forest Hospital. "It can be a warning sign for a more significant stroke in the future."

According to the AHA, up to 18 percent of people who experience a TIA will have a stroke within three months — and half of those strokes will occur within a few days. About one-third of people who have a TIA go on to have a stroke within a year.

Several days after her first TIA, Bonness found herself back in the emergency room. This time the diagnosis was a stroke.

TIA RISK FACTORS

Major risk factors for TIA include:

- * **High blood pressure**
- * **Diabetes**
- * **Heart disease**
- * **Atrial fibrillation**
- * **Smoking**

Source: American Stroke Association

What are the signs of a TIA?

The symptoms of a TIA are the same as those for a stroke, doctors say, only they are temporary and can sometimes resolve as quickly as they come on.

Amin points to the acronym **FAST** to recognize the warning signs of both TIA and stroke. The first three letters stand for: **F**ace drooping (typically on one side), **a**rm weakness or numbness (again, this is usually on one side of the body) and **s**peech difficulty, where an individual may struggle to string words together, may say something nonsensical or may have thick, slurred speech "where it sounds like the

patient's got marbles in their mouth," Amin says.

The final letter stands for **t**ime to call 9-1-1, and the same holds true when it comes to TIA, even if the symptoms stop before you get to the phone.

Another symptom to pay attention to is vision change, Amin says. "The classic type of vision symptoms that suggest a stroke or TIA is a blackout of vision. So if someone notices complete vision loss in just one eye, and it's described as kind of a nightshade coming down over one eye, if it's temporary or if it's lasting, that is an emergency," he says.

In fact, some stroke awareness campaigns use the acronym **BE FAST**, with the "**B**" standing for **balance** and the "**E**" representing **eye/vision** changes. Thinking back, Bonness says had she known about BE FAST — she had at least three of the symptoms — she "probably would have gone to the ER sooner."



Patient Education Continued

“It’s imperative that we don’t ignore those symptoms and seek medical attention very quickly,” Jivan says. “Even though they’re transient and they’re short lived, [TIAs] are associated with long-term, worse outcomes.”

Diagnosis and treatment can help prevent a stroke

Doctors can diagnose a TIA with a series of tests in the emergency room, including imaging tests to look for signs of narrowing arteries that lead to the brain, and blood work to rule out other conditions that present with similar symptoms. After a diagnosis is established, cardiac tests may be ordered to assess heart risks that may have caused the TIA, such as atrial fibrillation, an irregular heart rhythm that can increase risk for stroke.

The AHA also recommends that physicians assess a patient’s risk of stroke after a TIA, taking into account their age and other stroke-related risk factors, such as diabetes, high cholesterol and high blood pressure. Those at high risk may be hospitalized. Patients at lower risk may be prescribed medications, like statins or blood thinners, or referred for surgery to open up a narrowed artery.

And because behaviors like smoking, poor nutrition and physical inactivity can increase the likelihood of TIA or stroke, many TIA patients are counseled on risk reduction.

“We think about how to best manage those risk factors to prevent something like that from happening again,” Jivan says. Research suggests that up to 80 percent of

strokes after a TIA may be preventable when risk factors are managed.

After her stroke, Bonness, now 65, poured her focus into changing her lifestyle. In addition to taking medication for high blood pressure and high cholesterol, she altered her diet, set boundaries with her work, and carved out time for creative projects, including poetry and memoir writing.

“Your lifestyle matters — so all the stuff they tell you about eating healthy and managing your stress would have helped prevent this TIA for me,” says Bonness, who fully recovered from her stroke and was eventually able to go off all of her stroke-related medications. “And it certainly has helped me prevent any future strokes now, with the

lifestyle that I take very seriously.”

Rachel Nania writes about health care and health policy for AARP. Previously she was a reporter and editor for WTOP Radio in Washington, D.C. A recipient of a Gracie Award and a regional Edward R. Murrow Award, she also participated in a dementia fellowship with the National Press Foundation.



NIH Continued

Other drugs suppress only parts of the immune system. These tend to have fewer side effects and can be used for longer. Some of these drugs get rid of cells that make certain antibodies. Others target specific immune-system proteins. One such drug was recently the first new drug approved for lupus in a decade.

You may need to try several different drugs to find the one that works best to control your symptoms, Grayson says. It’s important to work with your doctor to balance quality of life with treating the disease, he adds.

Lifestyle changes can also help control symptoms. Movement is especially important for autoimmune diseases that affect the muscles, like myositis and MS, Mammen says. “We actually prescribe exercise,” he says. “It’s not optional; it’s part of the treatment.”

Talk with your health care provider about different activities you can try. Low-impact workouts like yoga, water aerobics, or walking can be helpful for some people.

Quitting smoking can help those whose disease affects their blood vessels, Grayson says.

Researchers are working to develop better treatments. NIH projects are bringing together scientists, nonprofit groups, and drug companies to find new treatments and research tools for autoimmune diseases.

Researchers also want to find ways to detect autoimmune diseases before they cause symptoms, Mammen explains. “Maybe there’s a time period where early treatment could put the brakes on one developing,” he says.

Source



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George King Bio-Medical, Inc is searching for persons who test positive for Lupus Anticoagulant.

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2. Upon acceptance into our program, donors are generously compensated for their plasma.
3. All associated expenses are paid.
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How can you make a difference?

Your plasma will be used in laboratories to aid in the diagnosis of other patients who have APS. It may also be used in research labs seeking improved tests and better treatments for this disorder. Human plasma is the best source for this critical laboratory product.



How to Manage a Disrespectful Doctor Submitted by Kim Nault

Redirect the conversation. If they speak disparagingly or raise a topic not related to the visit (say your weight), try, "That's not the reason I'm here. Can we go back to my tennis elbow?"

Point out the possibility of bias. You can alert the provider that you're feeling dismissed by saying, "I'd like to know you are taking me seriously." Or you can respectfully call them out: "You may not intend this, but when you say X, you're making an assumption about me that isn't accurate." You can also post a question in a way that reveals the bias. For example: "Is this the advice you would give to a young/white/thin/male person?"

End the appointment—or make it your last. If you are so uncomfortable that you no longer wish to be in the same room with the doctor/nurse/dentist, curtail the visit. You have a right to be treated with respect.

File a formal complaint. Many doctors' offices, medical groups and hospitals have ways for patients to speak up (anonymously or not); ask the office manager how. And if the experience affected your care, consider complaining to your states medical licensing board.

Go to a specialist. You can lower the chances of stigmatization by seeking out a provider who's specifically trained on the condition for which you need treatment; specialist are more likely to understand the challenges and may be better able to provide scientifically accurate information—in short, to offer less judgement and more support.

The Affordable Connectivity Program (ACP)

Written by: Tina Pohlman

What is the ACP?

The ACP is a federal initiative to help Americans access affordable, high-speed internet. It replaces the Emergency Broadband Benefit (EBB) enacted during COVID-19 pandemic.

What is the Benefit?

- ⇒ Up to \$30/month discount for high-speed internet services per household.
- ⇒ Up to \$75/month discount for high-speed services per households on Tribal lands.
- ⇒ A one-time discount up to \$100 for a laptop, desktop computer or tablet purchased through a participating provider per household.

Do I qualify?

Households with an income at or below 200 percent of the federal poverty guidelines may be eligible for the ACP. Households who also qualify for the following programs may be eligible

- ⇒ Qualify for the Lifeline program and those who participate in certain federal assistance programs, such as Medicaid, SNAP and SSI benefits.
- ⇒ Households that already use discounted internet services from a high-speed internet provider.

- ⇒ Receives benefits under free and reduced lunch program or the school breakfast program, including through the USDA Community Eligibility Provision, or did so in the 2019-2020 school year.



- ⇒ Households that participate in the Tribal specific programs such as Bureau of Indian Affairs General Assistance, Tribal TANF, or Food Distribution Program on Tribal lands.

How Do I Sign Up?

Eligible households will enroll through participating high-speed internet providers or directly with the Universal Service Administration Company (USAC).

Where Can I Go To Learn More?

Get the latest information and participating providers in your state:

Website: <https://www.fcc.gov/acp>

Text: INTERNET to 22777

Call: 1-833-511-0311



How to Help Your Loved Ones Manage Antiphospholipid Syndrome (APS) Written by Kimberly Hayes

Supporting a loved one with a chronic health condition can be a challenging, yet rewarding activity. This is because chronic health conditions, such as Antiphospholipid syndrome, can have a significant impact on a person's daily life and well-being, however helping them overcome some of its challenges can significantly improve their standard of living and promote good mental health. In this article by APSFA, we'll explore a host of helpful strategies one can employ to help their loved one manage a chronic health condition, starting today!



Assist with ADLs & Household Chores

Individuals with chronic conditions often struggle with ADLs (activities of daily living) that can hinder their ability to complete seemingly simple tasks such as cooking, cleaning, etc. Here are a host of activities you can help with to keep their home clean and make their daily life easier:

● **Help in Meal Planning:** Collaborate with your loved one to create a weekly meal plan that considers their dietary restrictions and preferences. Next, plan a weekly day to visit the grocery store to stock up on necessities and also include some easy ready-to-eat meals to keep in times of need. Post-cooking, store food in microwavable containers for easy access and eating.

● **Assist in Household Chores:** Depending on your loved one's condition, make a list of household chores they require assistance with. Next, create a chore calendar to keep track of tasks that need to be completed, for instance, you can volunteer to vacuum their home

once a week. For major cleaning projects, consider hiring a local cleaning service.

Help Them Manage Stress

Keeping stress in check makes a significant difference in helping those with chronic health conditions live healthier and happier lifestyles. Here are some of the best ways to support them in stress management:

● **Declutter Their Home:** As reported by Verywell Mind, living in a cluttered household can lead to increased stress and irritability. One of the best ways to declutter spaces is to get rid of excess furniture, decorations, and unused items. If your loved one is not comfortable discarding their belongings into the trash, consider donating or gifting items in good condition to local charities.

● **Take Them Outdoors:** Taking a leisurely stroll in a local park or natural space is one of the best ways to disassociate from stress. If your loved one is not comfortable going outdoors alone, offer to accompany them on walks or drive them to nearby nature trails, lakes, or viewing points.

● **Assist With Appointments & Medications:** Similarly, offer to drive them to their scheduled healthcare appointments, pick up medicines from dispensaries, and if possible provide them a daily calendar of medicines to take along with the doctor's prescribed timings.

Explore Viable Insurance Options

When it comes to meeting the healthcare costs of managing a chronic condition, having insurance coverage is paramount. However, if you or your partner has recently transitioned to working as a freelancer, finding good insurance can become tricky.

But, don't fret as there are still a host of options to explore:

● One option is to explore your partner's employment-based health insurance. Many employers extend coverage to spouses or domestic partners, making this a sound alternative to explore. However, be sure to carefully review the healthcare coverage to ensure it includes the cost of chronic conditions such as Antiphospholipid syndrome.

● Another avenue is to join the Freelancers Union, as they offer access to group insurance plans for independent works. Oftentimes these plans provide competitive rates and flexible coverage options.

● If you urgently need insurance coverage, COBRA (Consolidated Omnibus Budget Reconciliation Act), is an option to consider. COBRA allows you to retain our previous employer's insurance for a short period, according to K Health. However, you will be responsible for the full premium cost. While this can prove to be costly, it might still be less than paying for healthcare costs out of pocket.

Providing support to a loved one with a chronic health condition can significantly enhance their quality of life and well-being. From helping with ADLs to navigating the complexities of insurance, there are a host of helpful steps you can take to make their life easier and provide a supportive environment.





Listen To Me

Written by: Kami Morley Schindler



My name is Kami and this is my story.

In Jan 2004 I had to endure watching my Mother lose her battle to

Cancer. I was grieving the biggest loss of my life losing my Mom. I was under tremendous grief & stress. Little did I know then that I would have my own battle to face.

I was 37 years old with 2 little girls & my husband. In Feb 2004 I started to get neck pain, kind of like a pulled muscle. I thought I must of done it at work lifting something. Then it started radiating down my right side by my lung. Me being stubborn dealt with this the best I knew how. I continued to work, refusing to go to the doctor. This went on for a week. Finally I could not catch my breath, I couldn't move. Still wouldn't go to the doctor, stubborn & stupid I know. My family all tried to get me to go, but I refused. My Dad had a

chiropractor friend who came to my house to give me "an adjustment". Stupidest move, that almost killed me. The next couple days I laid on the couch begging the Lord to take me. I was grieving my Mom so much, I just wasn't in my right mind.

Finally after 2 weeks of this pain my step Dad showed up on a Monday and said lets go now. He took me to

the doctor, my blood pressure was crazy high like 195/90 something crazy like that. They did EKG's on me which were off the chart. I was given 2 or 3 nitro pills, which did nothing. The doctor sent me home and was told to stay out of work for 3 days and come back on Wed. Well Wednesday came and now my left leg had the worst "charlie horse" I came limping into the doctor office. The doctor saw me walk in and said, what's wrong, why are you limping? I told her my leg was hurting. She said you have two choices 1) go by ambulance or 2) go to hospital immediately you have a blood clot.

So my step Dad took me home, cause I insisted I wanted to take my shower first.

Then called my hubby to meet us at hospital. When I got to the ER they took me immediately back. My blood pressure was now like 204/101, they ran EKG's, leg doppler, MRI to find out I had 2 DVT's that traveled from my left leg to my right lung. So I had two PE's. I was hours to a day away from dying the ER doctor's told me.

They immediately started me on heparin. I was in the hospital for a week. I did a lot of damage to my lung because I waited so long (2 weeks) to go to ER.

I had all kinds of tests run on me to find out I had this big long word, antiphospholipid syndrome an auto immune disease. I couldn't pronounce it let alone spell it. Later through this fb group I learned the abbreviation of APS. I started out having to take 12mg warfarin for about 2 yrs. Then I was moved to 10mg for another 2 years, now I have been steady at 9mg since then.

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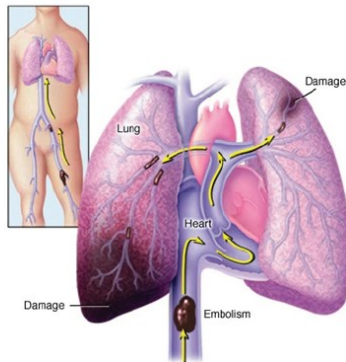
So now it's been 15 years later and I am still on 9mg

and haven't had another blood clot or PE. I did have a couple ER visits with possible TIA's. But ending up diagnosing me with Aura Migraines. I still get migraines a lot. Some where I lose partial vision. I have body/joint aches, no energy & just plain tired most days. But I have learned to live with it.

Most people don't understand because I "look" fine on the outside, but struggle a lot on the inside. I learned to just not tell people about my aches & pains because they don't get it or tired of hearing me complain. So I just go on with life as normal.

(Side note, with both my pregnancies in the 90's I had pre-eclampsia with both but delivered healthy babies.)

So just to educate others, my pain did not start out with the typical "leg pain" it started with neck pain. And because I damaged the bottom part of my lung, I only have half capacity of it. I have trouble holding my breath while I swim. But I am thankful I lived to tell my story. And now I have 2 grandchildren that I am grateful to be alive for.





Third Time's a Charm

Written By: Jennifer Bryant Cowling



I was 21, engaged and we found we were pregnant. Not exactly a shotgun wedding since the wedding date was already set, right?

We had a great wedding and honeymoon. A few months later, we had a wonderful baby shower. The week after the shower, I found out my son had died in utero. I was 28 weeks. I was induced and delivered vaginally. My husband and I got to hold Nathan and we were given photos, his footprints and the blanket and cap he wore.

I started injections twice a day and had Josh at 28 weeks. I'd gone to the OBGYN for a regular checkup and my BP was 185/135 and my kidneys were shutting down (protein in urine). I was started on magnesium to prevent stroke. Josh was 3lbs, 1 oz and born with both lungs collapsed and a small brain bleed.

Today he's a normal moody almost 19 yr old college student.

I really didn't have more issues with APS until 2016. My husband and I were at Disneyworld for our 20th anniversary. The last couple days there I was short of breath, but assumed it was my asthma (had since I was 2yrs old). I went to the ER when we got back and was told I was in severe congestive heart failure and needed surgery.

About 18 months after my heart surgery, I was at work (at a doctor's office) with a horrible migraine. I went to tell my boss I needed to leave. My boss had a doc to check my BP. It was higher than when I had Josh. The doc called 911. By the time they got to me, I couldn't move my left side. That was when I was put on warfarin for the rest of my life.

Throughout the last 20 years, I've been fatigued, stressed, sore. I've been headache, but for the most part, I shine it on. I cook and go to work and pay bills because there's no alternative.

Since my stroke, I've recovered 90%. My left hand is significantly weaker and I'm more clumsy. I just work on the weekends, so I can go to all the doctors during the week.

There's been pain and heartache, literally, but I am thankful for my little family and my "third time's the charm" baby.

I didn't bathe or work or eat much of anything for the next 3 months.

Two years later, I was pregnant again. I was at home and started bleeding. I was instantly hysterical. My husband happened to come home for lunch and found me on the kitchen floor. He carried me down the stairs of our apartment and drove me to the hospital on the army base where he was stationed.

I was yelled at for crying too loudly. As a teaching hospital, I must've had 30 ultrasounds, both abdominal and transvaginal and although I knew what was happening, nobody would say what was happening until a doc came and told me a D&E was scheduled for that afternoon. I was in hell again.

It was only several months later I learned I had APS and what it meant. Because we were at an Army hospital, the student doctors and technicians basically did every lab there was and genetic testing on both husband and me. I see other women who have had a half dozen or more losses before their diagnosis and the thought sickens me.

Two years after that, I was pregnant again. After four at-home tests, I called my OBGYN hysterically and demanded an appointment that day. I knew I needed to get on Lovenox injections!

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-



dy. 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:

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Blood Clots and Compression: The Dos, The Don'ts, and What You Should Know - A Summary from the of the PEP Talk National Blood Clot Alliance **By: Karyn Leigh**

I recently had the privilege to attend the PEP Talk presented by the National Blood Clot Alliance entitled "Blood Clots and Compression: The Dos, The Don'ts, and What You Should Know." It featured Dr. Suman Wasan, MD, MS, Clinical Professor of Medicine at UNC Heath, Vascular Medicine with Rex Vascular Specialists in Raleigh, NC, who is an expert on compression. Here are some of the key takeaways from the event.

How does graduated compression work?

Graduated compression is designed to work with the body's systems to move blood and fluids from the lower extremities to the heart. Our legs utilize a valve/pump system to move the blood - the valves are in the veins and prevent blood from moving backward; the pump is provided by our calf muscles, which squish the veins as we walk/move and push the blood up along the vascular system.

Post clot, our veins develop a scar where the clot used to be (these narrow and restrict movement of blood) and leaky valves (these create backups) that prevent our body from effectively circulating blood back to the heart. Compression helps by providing constant, measured pressure up the leg that pushes the blood (and fluids/swelling) from our outer legs inward and upward along the valve/pump system to the heart.

Graduated compression is most often used by people with post-clot related circulatory issues and those who have a condition called lymphedema, where the lymph system struggles to remove fluid and waste from the body.

Should I use compression stockings?

Studies show that compression stockings are most beneficial to people who have circulatory issues related to DVT clotting event(s). This condition is called post-thrombotic syndrome and is marked by swelling, pain, tingling, itching, heaviness, cramps, varicose veins, redness, and skin darkening of the leg(s). In about 5% of cases, post-thrombotic syndrome can cause ulcerations and skin breakdown.

One distinction to keep in mind is that compression hasn't been shown to prevent post thrombotic syndrome from developing over time, but it is strongly recommended to help those with post-thrombotic syndrome find relief.

Compression is also shown to reduce the risk of recurrence of thromboembolism in those who have had a clot. However, ongoing studies are incon-

clusive when it comes to people who have never clotted but have clotting markers (like antiphospholipid antibodies or FVL). Dr. Wasan advised that there is no real data to show that wearing compression stockings on a regular basis will prevent clot formation in those who have never clotted, but those with clotting markers but no clot history may wear them regularly if they wish. They may also consider wearing them on long trips (such as flights) where movement is restricted for periods of 4 hours or longer.

Are compression stockings a cure for post-clot circulatory issues?

Graduated compression is a helper (for maintenance), not a cure. Furthermore, graduated compression is not a replacement for movement. Even with compression, it is important to keep those calf muscles active during periods when one is sitting or standing for a long time to keep the blood flowing up your veins. This could involve taking periodic walking breaks or doing foot pushes/pumps (rocking the foot from toe to heel and back) or other leg exercises that encourage healthy blood circulation.

How soon after I've clotted should I start wearing compression stockings?

This is a discussion you will want to have with your doctor as each person's situation is unique. Some patients find it necessary, due to high swelling, to have their legs wrapped for a period of time prior to transitioning to compression stockings.

Can/should I wear my stockings at night/when sleeping?

Dr. Wasan feels that wearing compression in one's sleep is a matter of personal preference. Current studies show that there is neither benefit nor harm from wearing compression at night while sleeping.

How do I know which stockings to buy?

Dr. Wasan made it very clear that finding the right stocking means finding the compression that helps you that **YOU WILL WEAR**. Ask yourself the following questions:

Are stockings comfortable?

Are they something I can wear consistently?

Are the stockings I wear really improving the quality of my life/benefitting me? (to test this, try wearing them for a few days and then try a day without...if you feel worse without them, they're doing their job!)

Stockings come in two weaves - circular knit and flat knit. Circular





Blood Clots and Compression—Continued

knit are typically found over the counter and flat knit are by prescription (require fitting and someone to custom make the garment). Both weaves provide the benefits of graduated compression. Compression strengths can vary between manufacturing countries. In the US, stockings come in strengths of 15-20, 20-30, 30-40 and 50-60 mmHg. The lower the number, the weaker the compression. Most people use 15-20 or 20-30 mmHg as they are readily available over the counter.

In terms of style, stockings are found in calf, thigh, and full tights styles. Some are sheer and/or toeless. There are also compression sleeves, wraps, and crew style socks on the market. Some wraps have velcro to make it easier to take the garment on and off. Dr. Wasan feels that any of these can be beneficial depending on your individual circumstances.

Where is your swelling/pain? If you've only clotted in one leg, you may find it beneficial to only wear one stocking. If your issues are below the knee, you might only need calf-high. For those with groin area/high leg clots (such as those in the iliac), full tights might be helpful [of note, there is a study/trial now in progress, C-Tract, on the use of stents in groin/high leg clot patients to alleviate post-thrombotic syndrome. For more information, please see <https://bloodclotstudy.wustl.edu>].

How do I know I have the right size? How do I know I have a quality brand?

A properly fit stocking should be snug but not tight and should not pinch. If you are struggling with behind-the-knee pinching, you may benefit from a brand that makes calf-height in short, medium, and tall. In terms of quality, if you can easily stretch the garment or see the elastic through the weave, it is of lower quality. Typically, you get what you pay for, but the good news is that you don't have to break the budget to benefit; there are budget-friendly stockings out there that provide good compression at a reasonable price.

How many pairs should I buy?

Dr. Wasan advises that you start with a lower compression and then move up as tolerated. She also says that you may have to try a number of brands, styles, and compression levels before you find your perfect pair. Once you do, it is best to buy a number of them and rotate them. This not only will prolong the life of your stockings (which is generally about 3 months of daily use) but will also prevent the tedious task of hand-washing them every night for wear in the morning.

Are compression stockings the same as TED hose?

No, TED hose is used by hospitals as a post-surgical clot prevention measure. TED hose do not have the same graduated properties that compression stockings offer.

What about those compression pumps I see on Amazon? Are those good for people who have had clots?

Dr. Wasan warns against the use of any device that is not FDA regulated/prescribed by your doctor. These over-the-counter compression pump devices are touted by celebrity athletes as being beneficial for post-game

recovery. These devices are not regulated by the FDA, are not designed for people who have clotted, and there is no scientific evidence showing that they are of any real benefit to anyone. In fact, they may cause harm because over compression can further damage your circulatory and lymphatic systems.

So, to recap, studies show that those with post-thrombotic syndrome, may find relief from their symptoms with the consistent use of a quality compression stocking that fits them properly and is comfortable enough to wear every day. Ultimately, the decision to use compression stockings is one that should be made with the help of one's doctor and tailored to the unique circumstances of the patient.

For a full watch of this highly informative PEP Talk, please see the link https://us06web.zoom.us/webinar/register/WN_pBk4ktM8RJuM4uK_Y8WqXVQ



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