



ANTIPHOSPHO...WHAT?

APS Foundation of America, Inc. Newsletter
Volume 21 Spring/Summer 2011

June is APS Awareness Month

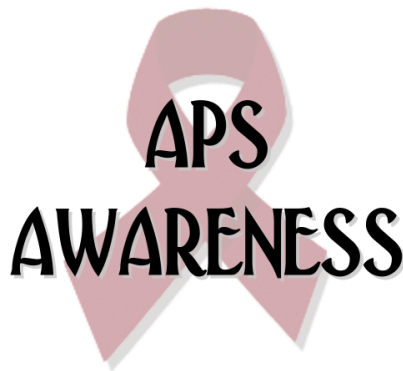
Written by: Tina Pohlman & Heidi Ponagai

With June being APS Awareness Month & June 9th being the Second Annual World APS Awareness Day, we are asking you to get involved with spreading awareness by sharing our newsletters, graphics, public service announcements and press releases on the social networks sites you belong to. We know many of us are on several of these addictive sites such as Facebook, Twitter and MySpace. If everyone shares one link, posts one bulletin, and/or tweets about APS Awareness and asks their followers to re-tweet it, we could potentially reach millions of people!

Links for our social networking pages are available on the front page of our website as well as on our support forum and newsletter. We already have a number of blinkies, badges and flair that can be added to blogs or used as avatars during the month of June.

We are asking you to talk about APS in your various support groups and even mention it in your non-APS support groups. Or, if you blog, write a blog about it and ask people to link to your blog post. The goal is to get APS to be a familiar name in the medical & autoimmune communities.

Where can you find this information? It is all over the place! But here are good starting places for you to begin educating those around you and in your network: <http://www.apsfa.org/media.htm> and here <http://www.youtube.com/user/APSFA>.



You will also find photo albums that can be shares on both our Facebook and MySpace Fan pages. We also have a tweet sheet located here:

<http://www.apsfa.org/docs/APSFA11Junetweets.pdf> These work great not only for Twitter but for Facebook as well.

Don't be afraid to contact your local media and ask them to do a story about you and your battle with APS. Explain why it is important for them to cover APS this month.

We realized that money is tight for many people so we haven't been actively soliciting for donation but we do ask you to check out our new designs available in our Café Press store

at <http://www.cafepress.com/apsfoundation>

Also be sure to check in the left hand corner, there are usually coupons there. Not only will you have a cool awareness item to wear but you know that 100% of the proceeds go to the APSFA to help us provide information packets to those who request them free of charge.

If you'd like to get involved and need help finding information, please contact us through the APSFA website. You may only be one person, but your one post could catch the eye of a new patient and bring them to our site so they can get the information they need and that is what awareness is all about!

So, while we continue to press on for a cure, please help us spread awareness on this horrible disease. It is time to cure this Silent but Deadly disease!

Click Below to Follow APSFA



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



We went from Winter to Summer it seems here in Wisconsin but today it feels like Spring. We are in full swing for APS Awareness Month and June 9th went great with lots of awareness spread on the internet. It is awesome to realize we are now 6 years old.

I would like to make a special thank you to the Kidd Family who had a fundraiser in loving memory of their daughter, Jessica Kidd-Vogelpohl. That was a huge kick off for fundraising for the APSFA this year and with their donation we will be able to get the scholarship fund rolling and add more to the research fund. We see the scholarship fund being used for people who are going into the medical field or are in the medical field. We hope you will continue support us in this venture. We are looking for help on writing guidelines for this scholarship, along with the application, etc. If you are interested, please contact me at tina@apsfa.org

There have been lots of new products added to our Caf  Press site. I can't keep up with all the new additions. Please bear with us as we get each design updated. Also, you may want to check out our new designs at www.cafepress.com/apsfoundation. Watch for more dragonfly items coming soon.

I am looking for a vendor who makes dragonfly jewelry as well. If anyone has ideas or finds one, please contact me at the above email address.

I am please to announce that my finger stick machine mention last newsletter generated a great deal of discussion across Facebook and other groups. Many people have now become educated on these machines and are finding out for a fact, they are not accurate for APS patients and have shared that information with their doctors. Education is Power!!

Once again, I hope this newsletter finds you in the best of health and with a perfect INR level.

Sincerely,

Tina Pohlman

President & Founder

APSFA Board of Directors

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

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

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



“We Have a Sick Puppy Here”

Written by: Abby Murphy

I am a 44 year old African American female who was diagnosed with the APS in 2000. I had had numerous miscarriages and my OB suspected I had APS so after another miscarriage he was able to take a sample of the fetus and that was when he was able to make his positive diagnoses.

I was finally able to sustain a pregnancy with the help of daily injections of heparin in my stomach for the first six months of pregnancy. I delivered a healthy baby girl on August 26, 2001.

Three days after having my daughter thru cesarean section I woke up at home with pressure on my chest and I drove myself to the emergency room. When the nurse took my blood pressure she yelled out "we have a sick puppy here" and people ran to me from all directions.

I was told within in 15 minutes that I had a heart attack and they needed my next of kin phone number. My mother and sister came and while they were there I had another heart attack right in front of them. The doctors could not believe someone of my age and medical background could be having a heart attack so they asked for more blood to be drawn because they assumed it was mix up with someone else lab results.

They sent me to have an angioplasty done but the procedure they needed to do they could not complete because the hospital was not a trauma hospital. I was then transferred by ambulance to a trauma hospital to have this procedure done. When I arrived the doctors would

come in groups and just stare at me for minutes trying to figure out why is this happening to someone like me.

The doctors would go into the waiting room and ask my family members questions such as does Abby use drugs. My family was then told by the doctors that my heart is in the condition of a person who has used street drugs for over twenty years.

The ER doctor told me they were not going to do the procedure I came over there for because they wanted to monitor me. Around 2 am in the morning the nurse was in my room giving me some oral medication and it was getting stuck in my throat and she told me to drink some more water to help it go down.

There was a Cardiologist sitting in the corner of my room reading my chart and that's when I started feeling funny. I told the nurse I couldn't breath and the last thing I remember was my heart monitors ringing like crazy then I fell back on the bed. When I woke up there was a nurse on the side of my bed and I told her she was the most beautiful sight I had ever seen and as I looked around my entire family was around my bed. I began to ask where had I been?, as I clutched my chest in pain, they wouldn't say anything other than get your rest.

The nurse tried to put an oxygen mask on my face and I began to fight her because it seemed like she was trying to suffocate me.

I later realized that I felt like I was truly fighting for my life because my heart had stopped beating and they had to put the paddles to my chest. After I coded and they got me stable they rushed me to the ER and did the surgery they were suppose to do in the first place. I have two stints in my chest one in the back wall of my heart and one in

the front. By the grace of God I am still here and fairly healthy and my daughter is now nine years old and we are both doing fine.

This is what
APS
looks like

Act in a “FLASH” to Treat Stroke

If you are having a stroke, every minute counts. Getting treatment within a few hours of your first symptoms is key. It could save your life or reduce your risk of being disabled. Call 911 in a flash if you recognize these signs:

F = Face: Sudden numbness or droopiness – especially on one side – or a severe headache.

L = Leg: Trouble walking or one leg that is weak or numb.

A = Arm: Numbness or difficulty holding up one arm.

S = Speech: Slurred words or trouble understanding others.

H = Hospital: Get to the emergency entrance of the closest one as quickly as possible.





A Canadian Girl Fighting for Help

Written by: Loren Gibbs

My name I Loren, I am 26 years old and I have APS. I was diagnosed when I was 23 but it was a fight to get answers. I live in Northern Ontario where doctors and specialists are few and far between. I started to get sick with various things at 21, skin abscesses, optical neuritis and at 22 was my first DVT. I was hospitalized because the clot kept moving, they got me on Coumadin and Lovenox injections for 3 months figuring the birth control was what caused it.



I got referred to a specialist in Sudbury who took me off thinners after 3 months claiming I was too young to get clots or have a clotting issue. Within a week I had another DVT. Back onto the Coumadin I went, back and forth to the lab 3 times a week because my INR wouldn't stabilize.

At this time I was pursuing my dream of becoming a veterinary technician and had just moved to a new town all alone. I was struggling through school, doctors appointments and blood tests never knowing what was actually wrong. My specialist told me I had a Protein C Deficiency and took me off thinners again, and once again another DVT within a week. So with that my GP decided

that specialist was not the one for me and referred me to a specialist in downtown Toronto.

Through all of this I still pursued my schooling despite my blood messing with my memory and feeling like a walking zombie 90% percent of the time. My fellows APS friends will understand how difficult that was.

I saw the new doctor at Sunnybrook Hospital on November 11 2008, he did tests and an ultrasound to find out I had 5 DVTs in my right leg. It wasn't until I returned up

North to school that I found out I had been diagnosed with APS. My GP up there had no idea what it even was so he told me to look it up online. This made me uneasy, a disease my doctor can't even explain to me. All he had to say was...at least it isn't blood cancer. I continued my schooling, sick everyday but very determined to at least be able to say I fulfilled my dream and became a vet tech and I graduated with .02 away from honor roll.

Since I graduated I have been fighting APS, its been very difficult. I have suffered from mini strokes, pulmonary embolisms, DVTs, I've had numerous surgeries but through it all I finally found myself a good team of

doctors. They look after me well, they explain everything clearly to me and have got me onto a better drug scheme to help out. They switched me a year and a half ago to daily Lovenox injections and an aspirin a day and since then I have had no more DVTs. I have had problems but no DVTs. The Lovenox injections do suck because my stomach is horribly bruised all of the time with nasty bumps and swelling that will never go away but that to me is just minor and I prefer that as opposed to DVTs and regular lab visits.

My family has been amazing, they help me 100% and if I didn't have them I wouldn't still be here today. They support me and they understand me, they deal with me when the APS has me extremely grouchy and sad. In Canada, information is just recently coming out and about to everyone, its very rare so I do my best to inform everyone I know what it is to spread awareness. The more people know; the closer we all are to a cure. I could go on and on for hours about the fights I have endeavored from this awful disease but everyone else knows as well what its like.

Stay strong APSers. God only hands you what he knows you can handle so in my mind this means we are some of the strongest people alive and we are living proof that anything is possible. **FIND A CURE!**

The One Document You Need in Case You Get Sick

Submitted by: Tina Pohlman

A living will – sometimes called a declaration or an advanced healthcare directive – governs your end-of-life wishes, and you should draw it up while you're healthy.

The document gives you the right to accept or refuse certain end-of-life care like artificial respiration, hydration and nourishment should you become ill. "If you don't want your life prolonged in this way, state that in your declaration," says Liza Hanks, a lawyer at Finch Montgomery Wright in Palo Alto, California. This is different from a Do Not Resuscitate (DNR) order, a form a doctor may provide to elderly and terminally ill patients to prevent the use of CPR in an emergency.

However, even when your wishes are stated, things can go awry in a crisis, so experts recommend that you also name someone who can advocate on your behalf, a person who

can be your healthcare proxy or agent. The key is choosing someone who's available (or able to jump on a plane at a moment's notice), trustworthy and unwavering in a crisis.

In most states, you'll set up your living will in tandem with naming your healthcare agent. The document used to designate this person is called a durable healthcare power of attorney, and is easy to set up, says Hanks. You don't need a lawyer for this or your living will. In many cases, you can get the necessary forms from your HMO, from a senior center or from a state medical association – or WillMaker software. In some states, the papers may need to be notarized or witnessed.

Reprinted from Woman's Day June 2011



Living with APS

Written by: Kisha Greene Tarlton

Living with APS is not easy

People look at me and think she don't look sick.

But they really have no idea how bad I sometimes feel.

My legs often feel heavy and I walk with pain

At night my legs keep me awake and hurting

My life has not been the same.

Out of nowhere the headaches hit me

And at times my vision becomes blurred

Which makes it hard to see.

I can't do the same amount of activities

No more dancing, or long walks for me

They wear me out, out to the point of fatigue.

I get confused and forget things very easily.

When I had a blood clot that went to my heart,

I thought "God is this the end am I coming home?"

He decided my work on earth was not yet done.

But, it is scary when new symptoms come for the

Same questions comes to mind "will the end come sooner"

For me when I feel ill, I leave it in God's hands, as I

should do but, I have to be honest and say that I worry

Still for I know my life will never be as it was before

APS attacked me and for loved ones this fact can be

Hard to face since they look at me and see someone who

From the outside is healthy but as I said before they can't

See the struggle and pain when APS attacks.

I fight a day-to-day struggle with my disease but I promise

Those that love me to try and be happy I will have my ups

and my downs. I have adjusted to this new way of life.

A life with APS.

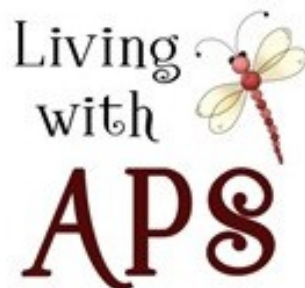
Diagnosed with APS in March 2006

Had to get a artificial heart valve (mechanical)

Kidney Failure

4 Strokes

And A lot more due to APS.



APS and Me

Written by Haley Rica Eason



I am 22 years old will be 23 on September 4th born and raised in Columbus, OH. It All Started out in May of 2010 when I started having chest pains my husband took me to

the ER where they said nothing was wrong. Then I made an appointment with my family doctor for him to tell me I had pulled a muscle. But the chest pains were not getting better and I went to the ER several more times and to my doctor. Well the last effort I went to the ER they said I was having heart palpitations and this was causing the chest pain so I set up an appointment with a cardiologist one of the best in my area. From then they ran tests and determined I suffered from heart palpitations and mitral valve prolapse. So the doctor put me on Toprol to slow my heart rate down and I found all this out in August of 2010.

After That I started developing numbness in the left side of my face, arm pain on left side, and really bad headaches. So my family doctor sent me to a neurologist. From There I got blood work after blood work. At first they thought I had MS but ruled that out because I was having muscle pains along with everything else. They ruled out that I had not suffered from strokes or heart attacks. After the blood work came back it showed my proteins in my blood were all messed up so they tested again and it was the same. The neurologist then told me I may have a clotting disorder. In Feb 2010 I suffered a miscarriage also in July 2010, he said this may have caused the miscarriages. So then he said I want you to see a hematologist. So I went, the hematologist ran the test again and it was the same. Then he told me I had APS, he discussed what it was and how it all added up. I am now on Plavix to help thin my blood and have to get my blood checked every four weeks. Living with APS is very hard at times. I just don't understand why me? But all I do is try to live life one day at a time. Also to live my life to the fullest.



Heparin Induced Thrombocytopenia (HIT)

Written by: Heather Klug, Pharm.D. Candidate - Reviewed by: Al Lodwick, RPh, MA

What is HIT?

Heparin-induced thrombocytopenia (HIT), also known as "white clot syndrome" or heparin-associated thrombocytopenia (HAT), is a severe immune-mediated drug reaction that can occur in anyone exposed to unfractionated heparin or low-molecular weight heparin (LMWH) products. However, the incidence of HIT in patients exposed to LMWH is less than that of patients receiving unfractionated heparin. Heparin or LMWH is mostly used to prevent or treat various clotting diseases but can be used for many other conditions. HIT is characterized by the formation of antibodies (heparin-dependent antibodies) in the blood that lead to the destruction of blood cells that are responsible for forming clots, called platelets. In later stages of the reaction, the platelets increase in number and can make patients more susceptible to forming clots in the extremities or cardiovascular system.

"About 50% of patients exposed to heparin will develop heparin-dependent antibodies. Approximately 3% of patients exposed to heparin will develop HIT. Complications are estimated to occur in 50% of patients with HIT."

What are the complications associated with HIT?

Complications of HIT can result in life- or limb- threatening clots or death. More specifically, clots can form in the legs or arms (deep vein thromboses or DVT) or lungs (pulmonary embolism or PE) or brain (stroke), arteries can become blocked and lead to limb amputation, or skin necrosis may occur.

Who is at risk for developing HIT?

Any patient exposed to heparin or LMWH at any dose is at risk for developing HIT. This includes, unfractionated heparin at full therapeutic doses, preventative doses, heparin flushes, or heparin coated catheters.

About 50% of patients exposed to heparin will develop heparin-dependent antibodies. Approximately 3% of patients exposed to heparin will develop HIT. Complications are estimated to occur in 50% of patients with HIT.

Patients that are at a higher risk for developing HIT include those with previous exposure to heparin, a past history of HIT, presence of heparin-dependent antibodies, or patients undergoing cardiovascular or orthopedic surgeries.

What is the treatment for HIT?

It is recommended that all heparin or LMWH be discontinued, including heparin flushes and heparin coated catheters. Switching to LMWH is not recommended in patients that develop HIT due to the presence of heparin-dependent antibodies and the likelihood that there is cross-

sensitivity between unfractionated heparin and LMWH. The recommended treatment for HIT in a patient that requires anticoagulation is a direct thrombin inhibitor such as lepirudin (Refludan) or argatroban (Argatroban), or danaparoid, which is a heparin derivative. Both lepirudin and argatroban are FDA approved for the treatment of HIT, but danaparoid is only indicated for clot prevention in hip replacement surgery. These agents are effective for the treatment of HIT and prevent complications associated with HIT. Warfarin is not recommended for initial treatment of HIT due to the possibility of further complications. Once platelet levels return to the normal range and a direct thrombin inhibitor is started, warfarin may be an option for long-term anticoagulation.

In a review article titled, Treatment of Heparin-Induced Thrombocytopenia, researchers assessed the risk associated with clots after stopping heparin in a patient with HIT, the current evidence supporting the use of direct thrombin inhibitors, the use of direct thrombin inhibitors in patients with a past history of HIT requiring anticoagulation for coronary procedures, and the risk for bleeding when direct thrombin inhibitors were used. Researchers found nine studies that provided information about HIT and treatment alternatives. They found that the risk of developing a clot after stopping heparin therapy due to HIT is at least 20% and may be as high as 50%. Therefore, a rapid act-

ing anticoagulant should be initiated once heparin therapy is stopped. The direct thrombin inhibitors evaluated were argatroban and lepirudin. Danaparoid is another alternative, but the studies did not meet the criteria for this review. Both argatroban and lepirudin were found to reduce the incidence of clots, death, and amputations related to HIT. The use of direct thrombin inhibitors in patients with a past history of HIT undergoing coronary procedures were found to have a complication rate relative to patients without a history of HIT. Finally, the risk of bleeding associated with direct thrombin inhibitors used in patients with HIT was found to be 6-18%. The result is consistent with the expected risk of bleeding related to these agents. Therefore, the researchers conclude that the use of direct thrombin inhibitors in patients with HIT has been shown to be beneficial in reducing complications related to HIT.

How is HIT prevented?

Since the incidence of HIT in patients exposed to LMWH is lower than the incidence of HIT in patients exposed to unfractionated heparin, LMWH heparin may be a consideration as first line therapy. If heparin is necessary, the duration of therapy should be limited to less than 5 days and the patient should be switched to warfarin if long-term anticoagulation is required. However, warfarin should not be started in a patient who has had HIT until the platelet levels are within the normal range. LMWH should not be substituted for unfractionated heparin if HIT should develop.

References

Coutre S. Heparin-induced thrombocytopenia. UpToDate® Online 11.1. Available at: <http://uptodateonline.com>. Accessed March 20, 2004.

HIT information page. Argatroban web site. Available at: <http://www.argatroban.com>. Accessed March 21, 2004.

Hirsh J, Heddle N, Kelton J. Treatment of heparin-induced thrombocytopenia. A critical review. Arch Intern Med 2004;164:361-9.



Lupus: A Primer

Submitted by: Dana Stuart

For most people, a few days of feeling tired, running a fever and having achy joints are signs of the flu. But nearly 1.5 million Americans have these symptoms every day. This may be a sign of a serious and sometimes life-threatening condition called lupus.

Lupus is more common in women than in men, and usually affects people between the ages of 20 and 40. Two to three times as many black women have lupus compared to white women. Lupus is also common in Hispanic, Asian and Native American women. Most people with lupus can expect to live a normal healthy life. But flare-ups can lead to serious infections, kidney damage, stroke or other complications. When flare-ups do occur, treatment is usually effective and can be life-saving.

What is lupus?

Lupus is a chronic (long-lasting) autoimmune disease. This means the immune system, normally designed to protect against bacteria, viruses and other germs, attacks the body's own tissues. Lupus autoantibodies target healthy tissue throughout the body, including the joints, skin, blood vessels, kidneys and brain.

No two cases of lupus are identical. One person may have a skin rash and arthritis, while someone else may have had stroke and suffer from kidney disease - all due to lupus.

The most common type of lupus is called systemic lupus erythematosus, or SLE, and it affects several organs. There are also forms of lupus that affect mostly the skin or that occur as a result of medication (drug-induced lupus).

What are the symptoms?

Nearly everyone with lupus has some degree of fatigue, which can be extreme. Because of the combination of fatigue, fever and joint pain, lupus may be confused with rheumatoid arthritis.

Common symptoms may include:

- Facial ("butterfly") rash across the bridge of the nose and cheeks
- Rash that develops after being in the sun
- Red, raised patches of skin
- Ulcers in mouth and nose (usually not painful)

- Swelling and pain in two or more joints
- Swelling of ankles or feet (possibly caused by a kidney problem)
- Pain when taking a deep breath
- Hair loss
- Fingers turning white or blue after cold exposure

How is lupus diagnosed?

There is no single test to diagnose lupus. If your doctor thinks you might have lupus, he or she will ask about your symptoms and past medical history. You will also need to have a complete physical exam. Laboratory tests may be needed to rule out conditions with similar symptoms. Some tests may include:

- Blood tests to detect signs of the lupus antibody.
- A skin biopsy may be needed if you have a rash.
- Blood tests can check for inflammation, clotting, anemia, kidney involvement and immune system problems.
- A urine test may help to show kidney problems.
- Liver function tests to show if the liver is affected.
- A chest x-ray can show problems in the lungs.
- A kidney biopsy may be needed if there is kidney damage.

If you have lupus, tests may show problems in several organ systems including the skin, joints, kidneys, blood, lungs or nervous system.

How is lupus treated?

Lupus can often be treated successfully. But no single treatment works for everyone, and treatment in one person may need to change over time. Your doctor will help you form a treatment plan that is right for you. It usually includes lifestyle changes, like getting enough sleep and protecting yourself from the sun.

Lupus can also be treated with medication:

- Nonsteroidal anti-inflammatory drugs (NSAIDs) reduce fever

“Regular occurrences of fatigue, sore joints and low fever may be a sign of lupus. Learn more about this autoimmune disease, its diagnosis and treatment.”



Seven Tips for Talking to Your Doctor About Pain

Submitted by: Todd Ponagal

Written by: Louis Neipris, MD

Make the most of the time you spend with your doctor to get the care you need. Be your own pain expert to get the most out of your office visit.

Here are seven tips to help you effectively talk about your painful condition.

Being accurate and specific about your

pain will help you get the best diagnosis and treatment. These tips are helpful if you have fibromyalgia, arthritis or other chronic pain conditions:

1. Choose your words to describe pain. Here are some examples:

- Sharp
- Stabbing
- Tugging
- Burning
- Tender
- Stiff
- Dull
- Deep pain
- Achy
- Pressure

2. Rate your pain on a scale of 0 to 10, with 0 being no pain at all and 10 being the worst pain ever.

3. Tell your doctor when the pain is at its worst:

- In the morning when you wake up
- During the day after activity
- In the evening before you go to sleep

- At night (interfering with sleep)

4. Describe other symptoms beside the pain.

- Flu-like symptoms: tired, achy feeling all over the body
- Nodules on your hands or elsewhere
- Rashes

5. Describe the location of pain.

Be very specific. Point to a specific location or more than one area on your body. Keep track of pain by marking an "x" on a simple outline drawing of the body. Take the picture with you to the doctor as a visual reminder.

6. Describe how your symptoms limit your daily activities.

Here is a scale from 0 to 4, with a description of each number.

0. You have pain, but you are fully active. The pain does not limit your activity.

1. You can do light work or sedentary work (office work) but can't do anything strenuous.

2. You can walk around and take care of yourself, but can't do any work activities or strenuous activity.

3. Your pain is starting to limit your ability to take care of yourself. You need some help with even the most basic things like dressing, bathing or cooking.

4. You are completely disabled. You need help to take care of your basic needs.

7. Keep a pain log.

Track your pain for a few days before seeing your doctor. In the pain log, keep track of items 1 through 6. Also, note what medications, both prescription and over-the-counter, you took to relieve the pain and whether they helped. Include any herbal preparations. Also note any complementary treatments, like a massage, a warm bath or meditation. And note if these provided any relief.

SOURCES:

- American Pain Foundation. Target chronic pain notebook Accessed: 11/18/2008
- American Pain Foundation. Manage your pain. Spotlight on fibromyalgia. Accessed: 11/18/2008
- National Palliative Care Research Center. ECOG performance status. Accessed: 11/18/2008

“Be your own pain advocate. Here are seven tips for talking to your doctor about pain.”





(Continued from page 7)

and the symptoms of arthritis. Some NSAIDs, such as ibuprofen and naproxen, are sold without a prescription. NSAIDs should be taken only according to a doctor's instructions. They can raise the risk of stomach ulcers. Also, they can worsen kidney failure in people with lupus who have kidney involvement.

• Corticosteroid medications, derived from the natural anti-inflammatory, cortisone, may be applied as a cream for mild rash. An oral corticosteroid, prednisone, may be taken when internal organs are involved. For a severe flare-up, a large dose (or bolus) is given by IV infusion over a few hours. Corticosteroids are potent medications that can cause many side effects. As a rule, these medicines are given in the lowest effective dose for the shortest period of time.



• Antimalaria drugs can help with treating skin rashes, sun sensitivity and arthritis. These drugs, which are commonly used to treat lupus, were originally used to treat malaria.

Continuous treatment with antimalarials may prevent disease flare-ups. Common side effects are headache and stomach upset. More rarely, these drugs can cause eye damage. You will need regular eye exams if you are taking these medications.

• Immunosuppressant drugs, such as Imuran, may be used if lupus affects the central nervous system or kidneys. These drugs work by preventing the production of immune cells. Nausea, vomiting, hair loss, bladder problems and decreased fertility are among the common side effects. Long-term use also raises the risk for cancer or infection.

• Other medications, such as methotrexate, dehydroepiandrosterone (DHEA) and immunoglobulin (proteins from human blood) may also be effective in treating lupus in some people.

SOURCES:

- Lupus Foundation of America. What are the symptoms of lupus? Accessed: 01/08/2010
- Hannahs Hahn B, Tsao BP. Systemic lupus erythematosus and related syndromes. In: Firestein GS, Budd RC, Harris ED, McInnes IB, Ruddy S, eds. Firestein: Kelley's Textbook of Rheumatology, 8th ed. Philadelphia, PA: W.B. Saunders; 2008.
- National Institute of Arthritis and Musculoskeletal and Skin Diseases. Handout on health: Systemic lupus erythematosus. Accessed: 01/08/2010

Antiphospholipid Antibody Syndrome: Defined

Submitted by: Heidi Ponagai

A disorder that increases the risk that blood clots will form in the veins and arteries. Antiphospholipid Antibody Syndrome (APS) affects many more women than men. Sometimes nicknamed "sticky blood syndrome" in the United Kingdom, it can appear on its own but is often associated with systemic lupus erythematosus (SLE or Lupus) and other autoimmune conditions. People with APS have high levels of antiphospholipid antibodies in their blood. These antibodies—immune-system proteins—increase the tendency of blood to form into clots, which can lodge in the veins and arteries.

People with APS are at increased risk of a host of problems such as anemia, deep vein thrombosis (a blood clot that forms in a deep vein), heart disease, kidney disease, stroke, dementia, chronic

disease, stroke, dementia, chronic headache, peripheral vascular disease, and pulmonary embolism (a life-threatening condition in which a blood clot travels to the lungs). In pregnant women, APS can lead to miscarriage, premature birth, and other pregnancy complications.

APS is diagnosed when an individual has a history of blood clots or of miscarriage and/or premature births and blood tests have shown the presence of antiphospholipid antibodies. The presence of the antibodies alone does not warrant a diagnosis of APS. Many people have antiphospholipid antibodies in their blood but do not have APS. As a side note, up to 40-50% of people with lupus, for example, test positive for the antibodies and may have both Lupus and APS.

Treatment for APS is aimed at thinning the blood to reduce blood clotting. The standard treatments are anti-clotting drugs such as

aspirin, warfarin (Coumadin), and heparin. As warfarin has been known to cause birth defects, doctors treat pregnant women with heparin. In addition, women with APS, especially those with a history of pregnancy complications, must be monitored very closely during pregnancy.

People with APS are also advised to stop smoking, exercise regularly, and eat a healthy diet to guard against other health conditions that add to the risk of developing blood clots, such as high blood pressure and diabetes. Individuals who have already developed these conditions must get treatment to control them.

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APS Foundation of America, Inc.

Our Mission Statement

Founded in June 2005, the APS Foundation of America, Inc. is dedicated to fostering and facilitating joint efforts in the areas of education, support, research, patient services and public awareness of Antiphospholipid Antibody Syndrome in an effective and ethical manner.

Sponsored by: **The Kidd Family**



Café Press—APS Awareness Items



We have a number of new designs & products for APS Awareness available in our Café Press store, including separate **Hughes Syndrome** and **Sticky Blood** lines. Some of our new designs are shown here and many are available in purple for Lupus as well. Our

creative team is working on new one of a kind designs and lines and many will be coming soon! There are even a few new items such as travel mugs, pet bowls, 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 percent of each sale from our store when you buy from it, so not only will you get a quality item, but you also make a donation to a worthy cause! Check out our store at the address below and be sure to check back often!!



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