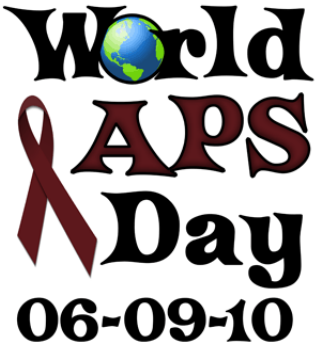
ANTIPHOSPHO...WHAT?

APS Foundation of America, Inc. Newsletter

Volume 17 Spring/Summer 2010

APS Awareness Month and World APS Day

Written by: Heidi Ponagai



APS Awareness month is right around the corner! This year is the 5th birthday of the APS Foundation of America, Inc. To celebrate, we have proclaimed June 9th as "World APS Day."

We hope that many of you will participate in World APS Day by wearing burgundy on that day and spreading awareness. Ask your friends and family members to do the same!

We are hosting a blog event through Bloggers Unite for World APS Day. If you are a blogger and want to participate, please visit our event site, sign up and join our event. Then, display our badge on your blog and on June 9th write something about how APS effects your life. You don't have to be a patient to participate. Friends or family members are welcome to join too! Don't have a blog? Notes on Facebook count too!

We have created an event on Facebook for World APS Day and have added items in our Cafepress and Zazzle stores with the World APS Day design on them. We've gotten some great feedback already on the quality of these items. We hope you will join us on World APS Day to color the world burgundy for APS awareness!

Speaking of awareness items, we will be adding 20 brand new APS Awareness designs to our Cafepress store very soon! These new designs will also be added to our new Zazzle store. If you're not familiar with Zazzle, check it out, they have a huge variety of shirts in sizes from infant to 6X. They also have some different items than Cafepress such as a wide variety of bags and mugs, square buttons, keychains, ties and even binders. As always, a small percentage of your purchases through our Cafepress and Zazzle stores goes directly the APSFA. Links: www.cafepress.com/apsfoundation & www.zazzle.com/apsfoundation

To celebrate our 5th birthday, the APSFA will be holding a fundraiser similar to the "Giving Tree" fundraiser that we have during the holiday season. Instead of decorating a tree with your donations, we will be stacking cupcakes around a large birthday cake. If you are interested in making a tax-deductible donation, please visit our website: http://www.apsfa.org/birthday.htm

We are also having a signature tag fundraiser. Signature tags are frequently used in forums (such as APS support forums!) or in emails. The signatures are awareness ribbons and we have many different causes available: APS, Lupus, FVL, Thrombosis, Infant Loss, Hughes Syndrome, heart attack, stroke and APS/Lupus. For a tax-deductible donation of $5.00 you will receive a personalized signature tag with the awareness ribbon of your choice! Please visit our website for details: www.apsfa.org/fundraisers/tags.htm

Finally, there are going to be big changes to the APSFA website. The site will be easier to navigate—with everything at your fingertips–and should load faster as well. We've tested it on many different browsers, including BlackBerry and iPhone and it definitely loads faster than the old site. The new site design will be live on June 1st, so be sure to check it out and give us feedback!

Patient Stories & Articles Needed!

We are in need of patient stories to feature in our newsletters, especially about men or children who have APS. 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

Spring is fully upon us and we are gearing for APS Awareness Month in June. It is so exciting that we turn 5 years old in June. I must thank all of the hard working, dedicated volunteers and medical advisors helping us continue to make the APSFA the organization it is today. Thank You for all that you have done!

As you read on the front page, the APSFA has proclaimed June 9th as World APS Day. We'd like to bring more attention & awareness to this "rare" autoimmune disease. So we are asking you to help spread awareness and to wear your APS Gear or burgundy on this day. Gear for World APS Day is available on both our CafePress store at http://bit.ly/d2nQWu and our Zazzle Store: http://bit.ly/cOuH6d

And since it is our 5th year in service, we are celebrating and everyone is invited. We will be having a large virtual cake and everyone who donates $10.00 or more will get a yummy virtual cupcake. So check it out at: http://www.apsfa.org/birthday.htm

Of course, individual and APSFA fundraisers will be occurring throughout the country to help promote APS Awareness and help support the mission. We have public service announcements that you can send to your local media. They can be found here: http://www.apsfa.org/media.htm Please keep an eye and ear out for our Press Releases!

The APSFA will be out & about sharing the patient perspective and provide awareness of APS throughout the month of June and also encouraging the public and medical community to Get in the Flow.

2009 as a whole proved to be a pretty good year for its 4th year. Here are some of the quick highlights: the APSFA home page benefited 76,839 people and made Press in 5 different media venues that we are aware of that benefited 100,000,000 people. As you can see we keep moving ahead by leaps and bounds. For the full year end report: http://bit.ly/c58yIS

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

Special thanks to Candy Czernicki for proof reading the articles.

As you can see we are all unique and none of us presented the same.

We are the Faces of Antiphospholipid Antibody Syndrome

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Antiphospholipid Antibodies On the Beach
A Patient's Perspective

Written by: Dana Stuart

The APS Foundation of America's Board of Directors sent me to Galveston, Texas this year for the 13th International Congress on Antiphospholipid Antibodies. I was proud to represent the foundation at this event and I have a great deal of information to report to you because you are the reason this organization exists. But before I can proceed, I want to explain what the International Congress on Antiphospholipid Antibodies is all about so you have a better understanding of what I am talking about. I am explaining all of this in layman's terms as I didn't even know what this congress was all about until I went to Texas and saw the congress in action. I hope to share this information with you not only from a patient's perspective but also from a social worker's perspective. I also want to add that this is my personal perspective on the Congress and although I was there as a representative of the APSFA, this article is my opinion.

Leslie Cornfeld, APSFA representative presenting the winner of the Young Investigators Award, Kristi Allen, with her check and plaque. Silvia Pierangeli, PhD in the background. The APSFA sponsored the Young Investigator Award for Ms. Allen.

The International Congress on Antiphospholipid Antibodies is a group of international physicians and researchers who study APS and determine the course of treatment for all patients with APS. They set the standards for diagnosis and treatment and every three years they assemble at this conference to discuss and evaluate changes that they will recommend based on their research. Basically they bring all of their information to the table, evaluate it, and then set the official standards and course of treatment for the next three years.

So why do the researchers only meet every three years and not every year? Based on my experience with grants as a social worker, I believe that most grants are issued on a three year basis. A grant (or several of them combined) are issued for three years and during those three years, a study (usually several) are conducted to determine whether or not a certain hypothesis is statistically significant or not. These studies can make or break the outcome for new treatment. It is important for APS patients to participate in APS research studies and to provide honest and accurate information so the outcome is not skewed. Chances are that your study will be discussed at this Triennial International Congress and CAN make a difference. The APSFA was proud to support and issue a grant to the researchers at this congress. During the congress, researchers have a poster session and each researcher presents their information to the congress who takes it into consideration when they determine whether there are any changes to the criteria for diagnosis and treatment.

Now that I've explained what the International Congress on Antiphospholipid Antibodies is, let me tell you about my own personal observations as they are tied in with my concerns. I always feel it's best to present bad news first and then finish on a positive note. First of all, there was no consensus on a lot of information presented at this congress. There were many heated debates and I found no resolution in hearing that some physicians still think of APS as a *"waste basket diagnosis"*. Nevertheless, while there's clearly still a group of physicians who think APS patients are crazy, always remember you are the patient, and you are also the customer. Thankfully, in America, you can still shop around for a different doctor or a second opinion.

Unfortunately, there wasn't a lot of patient-physician interaction at the congress. There were actually very few patients in attendance but thankfully there were enough of us to continue with the patient sessions. These sessions were facilitated by well known physicians in APS research; however, one of them refused to hear any patient stories. This very same physician is one who very blatantly stated that anti-cardiolipin levels under 40 are NOT IMPORTANT. That is like saying you are pregnant but your levels aren't high enough so you aren't really pregnant. What happened to positive is positive?

I do not feel that the patients were well represented at this conference. This concerns me because the APSFA has been gathering patient data through patient surveys through the support forum for the past five years. Although they have offered this information, only one physician has ever taken them up on this offer. There was one researcher, however, who did advocate on our behalf very well. She wasn't a physician. She was a nursing professor at the University Hospital in Houston and we are very happy she was there with a clear picture of common issues faced by APS patients. She had clearly taken the time to know us as an organization and she knew many of our members personally although she did not state any names, only spoke of our founders, and she had permission to do so. We are very happy that she is teaching nurses about APS, albeit she only covers one small portion of the country, but that's one more advocate than we had before. So we'd like to say thank you Susan Matthews!! I would also like to thank the APSFA's Medical Advisor, Gale McCarty, MD for all of her hard work representing the APSFA at this congress and

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Catastrophic APS – A Critical Piece of a Newly Recognized Disorder?

Written by: Natalie Alves

While most people who develop a blood clot in their vein have a deep vein thrombosis (DVT) or a blood clot in their lung (pulmonary embolism or PE), a very small number of people who develop blood clots have a more serious and often life-threatening syndrome called *thrombotic storm*. People with thrombotic storm experience more than one blood clot in a short period of time. These clots occur in different and sometimes unusual locations in the body. This very aggressive and serious form of blood clotting is often difficult to treat, and there is very little research or documentation of this disorder. Although research on *thrombotic storm* is still in nascent stages, scientists believe the disorder may be associated with an existing condition or situation that predisposes a person to blood clots such as infections, pregnancy, and, notable for this group, APS. However, unlike those who have an isolated DVT or PE, people who are at risk for thrombotic storm go on to experience much more severe symptoms after the initial clot forms. Experts believe catastrophic antiphospholipid syndrome (CAPS) is a form of *thrombotic storm*.

> **"Experts believe catastrophic antiphospholipid syndrome (CAPS) is a form of thrombotic storm."**

Thrombotic storm has been seen in children and adults. Recently a research study has been spearheaded by two doctors at the John P. Hussman Institute for Human Genomics who have experienced the torment of TS firsthand. On December 12, 1998, Margaret A. Pericak-Vance and Jeffery M. Vance lost their son, 14-year-old Jeffery Joseph Vance, to the disorder (www.jjvance.org). The healthy young athlete, scholar, brother and extraordinary young person wanted to grow up and be a geneticist like his parents. He was a gentle and generous person, giving his time and energy to others. Now the research investigation into the unexpected and fatal blood clot that caused his death may give hope to other families who have suffered similar tragedies. The Vance's are not only raising awareness of these deadly form of blood clots among doctors, but they have also teamed up with six different institutions representing seven unique specialties, in order to elucidate the symptoms, progression, and possible genetic factors that contribute to this rare, but serious disorder. Dr. Thomas Ortel from Duke University, one of JJ's doctors, is the lead clinical investigator of this study.

The researchers affiliated with the study met in Miami in mid-April and used their medical diversity to further shape the definition for TS based on research from different case studies of the disorder representing previous and current data from each specialty. Because TS had never been given a concrete definition, the symptoms have often been overlooked, which can be lethal since TS needs to be treated quickly and aggressively.

These researchers are now turning their focus towards recruiting patients and raising awareness of the disorder. Researchers will track patients over time and use detailed data from family history information to identify any potentially inherited patterns in the families of patients with TS. This will help researchers identify genetic factors that may contribute to this syndrome, and aid in the search for ways to predict, prevent, and treat TS. They are looking for participants!

Individuals who *were* age 55 years or younger at the time they experienced two or more of the following may be eligible to participate:

- Two or more distinct clots (in any location) in a short period of time
- Clot(s) in an unusual location (e.g. not the leg or lung)
- Clots progressed, or the clots came back when not expected to
- The response to treatment did not go the way the doctor thought it should (e.g. there was a poor or unusual response to treatment)

For those who would like more information about the study, they may contact study staff at 877-740-7744 or via e-mail at MIHGTS@med.miami.edu. In addition, you may visit the following websites:

www.thromboticstorm.com

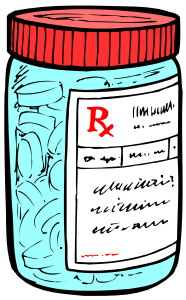
www.hihg.org

htc.medicine.duke.edu

Warfarin and Its Replacements—An APS Perspective

Written by: Al Lodwick, RPh, MA
Certified Anticoagulation Care Provider

The majority of readers of this article will know that APS is not well understood. This is one of the reasons that there has not been a drug developed specifically for the treatment of APS. Warfarin was on the market for the treatment and prevention of blood clots for about 30 years before APS became a recognized syndrome. Since there were no other medications nearly as effective as warfarin, it became the treatment of choice by default rather than by design. There are no studies that conclusively show that warfarin is superior to placebo or other medications for treating or preventing APS-related clots. The key point to notice here is that the fact that it is not approved for APS by the United States Food and Drug Administration (or any similar body in another country) does not prevent physicians from prescribing it when they decide that it is in the best interest of a patient.



There are two, new products that are in the late stages of development (or on the market in some countries) that are possible replacements for warfarin. The generic names of these drugs are dabigatran (da-BIG-a-tran) and rivaroxaban (riv-a-ROX-a-ban). So far there are no published articles showing effectiveness in APS patients. However, this will not necessarily prevent physicians from prescribing them to APS patients just as is done for warfarin.

Insurance coverage may be another issue. Insurance companies have traditionally been reluctant to pay for unapproved and especially expensive, new therapies. A check of online pharmacies reveals that the charges for these new drugs are in the range of 5 to 15 times more expensive than warfarin.

What is the answer to this dilemma? You may not like the word but it is politics. Pressure needs to be kept on sources of funding to pursue studies that could lead to these new agents being approved for APS. Pressure also needs to be kept on insurers to approve payments for the new drugs. How do you do this? Making a donation to APSFA is one effective method. The more money an organization has the louder its voice can be. Every day on the news we see examples of the wheel that squeaks the loudest getting greased. Healthcare funding agencies make decisions about putting a dollar amount of your quality of life and you need to do so too.

Faces of APS & Men with APS Ads

Written by: Heidi Ponagai

Included in the downloadable version of this newsletter is the full page ad that the APSFA created with the pictures that you, the patients sent in during our call out a few months ago.

This ad is featured on the back cover of the Lupus Journal and looks amazing in glossy, full color!

As stated when we sent the call out, we will eventually feature your faces and stories on the website. We are working on this and hope to have it ready by June, if not shortly after.

We also have another ad that is in the "Final Program Book" that was given out to everyone who attended the 13th International Congress on Antiphospholipid Antibodies—patients and physicians alike.

This ad features Jason Strauss, a young man who died from CAPS in 2009. We wanted to make an ad to bring home the fact that this disease is not just a woman's disease. Jason's ad is also included in the downloadable version of this newsletter.

Unfortunately, we never got to know Jason as an APS patient because he was diagnosed shortly before he passed away. But we have learned much about him through his sister, Tarra.

She writes, "*My name is Tarra Dodaj. I lost my twin brother Jason suddenly on January 19, 2009 to CAPS (Catastrophic Antiphospholipid Syndrome). He was diagnosed with Lupus and APS only weeks before his death. Jason was the kindest, most loving and generous man I had ever known. Jason would give you the clothes off of his back if he thought you were in need. Jason had a passion for community service and it showed through his generous donations to many causes.*"

Both ads are also going to be available for download alone the APSFA website: http://www.apsfa.org/downloads.htm

APS

It isn't *just* a pregnant woman's disease.

Jason Strauss

1972-2009

Died of Catastrophic Antiphospholipid Antibody Syndrome (CAPS)

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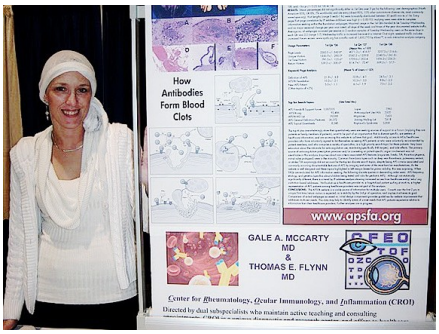
Leslie Cornfeld for also representing the APSFA and for presenting the Young Investigators award on their behalf.

My suggestion for the next congress is to have interactive patient sessions where the physicians can meet with and talk to the APS patients in attendance. I think this will add value to the patient sessions. I had hoped there were going to be patients speaking at the congress because the APSFA had offered to do a presentation during the patient sessions. Unfortunately, it seemed they didn't really want to hear from the patients. What I would like to see in future Congresses during the patient sessions are actual APS patients sharing their stories with other APS patients and physicians. Overall, I guess my biggest concern is that the patient really has no voice at the International Congress on Antiphospholipid Antibodies.



Dana Stuart posing by Dr. Gale McCarty's board in the APSFA's booth at the 13th International Congress on Antiphospholipid Antibodies

The International Congress is a time to bring new information to the table and the information that the patients could provide is not being heard. If you would like to request more patient representation at these congresses, which ultimately results in your diagnosis and treatment, please, be an advocate. Goodsearch the International Congress on Antiphospholipid Antibodies, write to their organization and state your requests. As a social worker, I am a firm believer in self-determination, equal representation and the right to have a voice. This is your right and you need to speak up about it. I am doing so right now in this article, and this is very public. So please have the courage to do so in private. What's the worst thing that can happen? They refuse to listen? They already aren't listening and the world hasn't come to an end yet. So what's the best thing that can happen? Physicians would allow patients to be heard by those physicians setting the course of diagnosis and treatment for those patients. Seems like a reasonable request to me. Especially since without the patient, they have no research. Many of your donated dollars have supported their research. At this very congress, the APSFA funded a research grant.

Now onto what I learned at this congress, there are some positive things here. I promise.

1. There are currently no mandatory continuing medical education units required of physicians. In other words, there is nothing set in stone that says a physician MUST learn about APS. So until that happens, there will still be ignorant physicians in respect to APS.

2. Sadly, in spite of warnings issued by the manufactures themselves, home INR machines were still promoted at the congress. Let me state this in layman's terms as well. They are not accurate in APS patients and this is in the disclosures. However, it will not be disclosed verbally unless you ask the question in a very specific manner. If you don't ask the question just right, the sales people do not have to answer. Let me assure you these machines are being investigated by the FDA. I hate having blood draws as much as the next person but currently, that is still the most effective and safe method of measuring your INR. Until the FDA states that these machines are safe to use, please do yourself a favor and read the warnings issued by the manufacturers themselves. You can find the links to all of this information on the APSFA's links page: http://www.apsfa.org/links.htm.

3. New trends have been discovered and will be researched over the next three years to evaluate their relevance. They include a family history of migraine headaches, clinical presentation trends such as spontaneous fractures, stomach problems, mad cow disease, Atypical MS problems such as ataxia, Meniere's Disease and other ear, nose, and throat issues.

4. Currently there is no change in the diagnosis and treatment criteria of APS patients. This is good because it means that what they know is tried and true. Sadly, however, women will still need to have three miscarriages or one stillborn before being tested. Therefore, if you already have APS symptoms and a family history of APS, Lupus or auto-immune disease, my personal opinion is to go ahead and ask your doctor for the blood tests. It's better to be safe than sorry. No one should HAVE TO lose three children before they are tested for this "syndrome".

5. You may begin to see prophylactic treatment for travel including 10,000 units of heparin to be administered or self administered a day prior to long travel.

6. Currently cognitive dysfunction is still the #1 complaint of APS patients and for those with lupus overlap, psychiatric problems. This could be interpreted in any number of ways by the patient, so don't read too much into it as of yet.

Overall, I thought the Congress was really informative and I'm so glad that I was able to go and represent the APSFA. I hope to see some of my suggestions implemented at the next Congress. I had a great time meeting other APS patients and it was fun schmoozing with the doctors whose articles I've been reading all these years! It's always nice to be able to put faces to the names. I even attended the "Taste of Texas" farewell dinner and dance.

The APSFA does plan on attending the next Congress in 2012 which is in Rio de Janeiro, Brazil. We will be fundraising for this from now until the next Congress. More information on our fundraising efforts can be found on our donate page at: http://www.apsfa.org/donate.htm

Laboratory Tests Used to Diagnose and Evaluate Lupus

Written by: Tina Pohlman

Lupus is characterized by abnormalities in many laboratory test results. These abnormalities are different for every patient and they vary significantly during the course of a patient's disease. The serial evaluation of an individual's tests along with the physician's observations and the patient's history determine the diagnosis of systemic lupus erythematosus (SLE), it course, and the treatment regimen. All laboratory values must be interpreted in light of the patient's present status, other correlating laboratory test results, and coexisting illnesses.[1]

This article describes the major tests used to diagnose and evaluate SLE and provides information on their rationale and clinical usefulness.

Diagnostic testing relies on two concepts, sensitivity and specificity. The first term refers to whether a test is likely to miss many cases of the disease or disorder for which the patient is being tested. The second refers to whether the test is helpful in narrowing the diagnosis to the condition being tested for.[2]

Antinuclear Antibody (ANA)

A positive result for the presence of these antibodies, which your immune system produces, means your immune system is "stimulated". That's a common finding if you have SLE or another autoimmune disease. The ANA is close to 100% of patients with active SLE. However, it is also positive in 95% of patients with mixed connective tissue disease, in more than 90% of patients with systemic sclerosis, in 70% of patients with primary Sjogren's Syndrome, in 40%-50% of patients with rheumatoid arthritis, and in 5%-10% of patients with no systemic rheumatic disease.[1] ANA testing is thus highly sensitive but not specific.[2] The sensitivity and specificity of ANA determinations depend on the technique used.[1]

Anti-Sm

Anti-Sm is an immunoglobulin specific against Sm, a ribonucleoprotein found in the cell nucleus. This test is highly specific for SLE; it is rarely found in patients with other rheumatic diseases. However, only 30% of patients with SLE have a positive anti-Sm test.[1] It may be unique to SLE; a finding with low sensitivity but high specificity.[2]

Anti-dsDNA

Anti-dsDNA is an immunoglobulin specific against native (double stranded) DNA. This test is highly specific for SLE but not particularly sensitive and it is not found in patients with other rheumatic diseases. Anti-dsDNA is found in at least 50% of SLE patients at some time.[3] For many patients with anti-dsDNA, the titer is a useful measure of disease activity. The presence of anti-dsDNA is associated with a greater risk of lupus nephritis.[1]

Anti-Ro (SSA) and Anti-La (SSB)

These immunoglobulins, commonly found together, are specific against RNA proteins. Anti-Ro is found in 30% of SLE patients and 70% of patients with primary Sjogren's Syndrome. Anti-La is found in 15% of people with SLE and 60% of patients with primary Sjogren's Syndrome. Anti-Ro is highly associated with photosensitivity both are associated with neonatal lupus.[1] These antibodies often accompany the Anti-Sm.[2]

Complement

Complement proteins constitute a serum enzyme system that helps mediate inflammation. Complement components are triggered into an activated for by such immunologic events as interaction with complexes. Complement components are identified by numbers (C1, C2, etc.) Genetic deficiencies of C1q, C2 and C4 although rare, are commonly associated with SLE. A test to evaluate the entire complement system is called CH50. The most commonly measured complement components are the serum levels C3 and C4.[1] The total amount of complement in the body at any given moment is finite. Therefore, if a complement has been drawn to sites of immune complex activity, there will be lower than normal levels in general circulation. In SLE, at least in active disease, serum complement levels are low. This pattern is also helpful in monitoring treatment.[2]

Erythrocyte Sedimentation Rate (ESR) and C-Reactive Protein (CRP)

Tests for ESR and CRP are nonspecific tests to detect generalized inflammation. It's specificity is very low but it does indicate something is amiss. Levels are generally increased in patients with active SLE and decline when corticosteroids or nonsteroidal anti-inflammatory drugs are used to reduce inflammation. However, they do not directly reflect disease activity.[3]

Antiphospholipid Antibodies (APLs)

APLs are autoantibodies that react with phospholipids. Recent data indicate that APLs recognize a number of phospholipid -binding plasma proteins (e.g., prothrombin, β2 glycoprotein 1) or protein-phospholipid complexes rather than phospholipids alone. APLs are present in 50% of people with SLE. Antiphospholipid Antibody Syndrome occurs in 50% of SLE patients who have the lupus anticoagulant. This syndrome is characterized by a persistently positive lupus anticoagulant or medium to high titer Anticardiolipin or anti- β2 glycoprotein 1 in the clinical setting of thrombosis, fetal loss, multiple first trimester losses, or preterm birth from severe placental vasculopathy.

APLs and Antiphospholipid Antibody Syndrome (APS) may also occur is patients

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without SLE. APLs are detected in 3 types of laboratory assays:

- **Lupus Anticoagulants.** Lupus anticoagulants are APLs that inhibit certain coagulation tests, such as the activated partial thromboplastin time (aPTT), dilute Russell viper venom tme (dRVVT), and kaolin clotting time (KCT). Although the antibodies act as anticoagulants in these laboratory assays, they are not clinically associated with hemorrhage, but with thrombosis, pregnancy loss, and other manifestation of the Antiphospholipid Antibody Syndrome. Most lupus anticoagulant antibodies are directed against β2 glycoprotein 1 or prothrombin.
- **Anticardiolipin antibodies (aCLs).** Sensitive enzymes-linked immunoabsorbent assays (ELISAs) using cardiolipin as the putative antigen are commonly performed to detect aCLs. In patients with Antiphospholipid Antibody Syndrome, most antibodies detected in the Anticardiolipin ELISAs are directed against the cardiolipin-bound β2 glycoprotein 1.
- **anti- β2 glycoprotein 1.** Because ELISAs do not recognized cardiolipin unless β2 glycoprotein 1 is present, anti- β2 glycoprotein 1 detection assays have been developed. These assays have revealed that anti- β2 glycoprotein 1 antibodies may be more strongly associated with Antiphospholipid Antibody Syndrome than are the anticardiolipins.[1]

Clinically, APS has also been associated, in significant proportions of patients, with several other disorders. They include particular neurological problems, notable seizures or migraine headaches; joint pain and inflammation; livedo reticularis, patch discoloration of the skin caused by dilation of small blood vessels; avascular necrosis of bone (even when corticosteroids, with which this condition usually associated, are not being taken); leg ulcers; hemolytic anemia; and various other troubles traceable chiefly to circulatory problems, including thromboses both major and minor. All APS-related difficulties are exacerbated by smoking and uncontrolled blood pressure, diabetes, and high cholesterol.[2]

Resources:

1: Lupus: A Patient Care Guide for Nurses and Other Health Professionals. 3rd Edition, National Institutes of Health, National Institute of Arthritis & Musculoskeletal & Skin Diseases. 2006

2: Living with Lupus: The Complete Guide, written by Sheldon Paul Blau, MD & Dodi Schultz, 2nd ed., rev. and updated 2004

3: Lupus: You Can Take Charge of It, written by Victoria Scanlan Stefanakos, 2005

Why Me?

Written by: Anna Expósito from Barcelona, Spain

It was Monday, Feb. 2nd, and I suddenly started having difficulty breathing. I thought it was asthma and didn't pay any further attention to it. But as days went by I started feeling worse so I finally went to hospital and was diagnosed with pneumonia. After several days at hospital, the doctor decided I could go back home.

Once at home, the symptoms started again along with strong chest pain. I went back to see the doctor and once I told him my new symptoms, he was concerned and an hour later, after a contrast CT, I was diagnosed with a bi-pulmonary embolism caused by a thrombosis in my leg that no one had seen the days before.

I felt like dying. It was hell. I couldn't believe what I was being told. It was very hard to cope but it was even harder when days after that diagnosis I was diagnosed with a new disease, Antiphospholipid antibody Syndrome. I thought it was a horrible nightmare and that I'd wake up in any minute, but it wasn't, it was real! And this is the reality I have had to assume since February, 2009.

It's been (and still is) hard. It's not only you who has to assume what's going on, how your life is to change now and forever, but your family and friends. People don't notice any change in you after being diagnosed, so they don't really think you're "that" ill, that you can't do everything you used to do before being diagnosed, and that you have to take care of yourself more now than ever. They don't understand that your brain is all the time wondering: Is this pain a new thrombosis? Am I having another embolism? Is it a stroke? Or is it only that my body is stiff today?

People can't imagine the fear you have to go through any time you feel something different in your body, and the worry you sometimes feel when thinking about your incurable and long-life disease. The same question always comes to mind: WHY ME? I'm a good person, I always try to help others, I've never smoked and never eat junk food, I'm was a healthy person, again, WHY ME? But you will never get an answer!

That's when you have to change your mind!!! If you can't beat the enemy, join him! This is what I have tried and am still trying to do! I'm trying to live my life the way it comes. I can't change reality: I have APS and I want to enjoy my live as much as I can!

I would like to thank my family and my friends. Without their support, I wouldn't be able to live my life with APS.

Through the Eyes of APS

Written by: Lori Sullivan

My purpose in writing this story is to help those living with a person who suffers from APS get a better understanding of what their lives are like. Some of our loved ones don't understand our illness, are in complete denial or because we do not look ill, they question the severity of our disease.

I have been ill for 8 years, and was diagnosed with APS in October of 2008. I have gone through every treatment from Plaquenil®, (which I am allergic), to Rituxan®, (which failed). The only alternative I have left is IV/IG (Intravenous Immune Globulin).

On a typical "bad" day, I wake up at 7:00 am, and get my two daughters off to school. Some days I know as soon as I wake that it is going to be a bad day. Other days I feel fine, but an hour or so goes by and I can feel the illness wash over me. I become hot, pale, weak and extremely fatigued. I record my temperature daily for my doctors though it is disheartening – most days it is around 100.5.

I then lie down because my body is depleted of energy. As I lie there, I think of all the things that I need to do for that day and wonder if I'll be able to get any done. I start feeling guilty, and I get up to do some light housework, but half way through I'm exhausted have to go back to lie down. I dread having to take a shower, knowing that when I am done, my 100.5 fever will get worse and will take a couple of hours to come back down.

By 3:00 pm, my daughters are returning home from school. This is the worst part of the day for me. My body feels like I have climbed Mt. Everest, and I am too weak to even hold a conversation.....more guilt kicks in. They get frustrated when they see me lying on the couch day after day. They miss the Mom who was once a ball of energy.

In the evening, my husband comes home. Either I don't have the energy to cook, or I throw something easy in the oven and either way I feel guilty. After supper, I am ready for bed around 7:00 pm. Before I fall asleep, I pray for the next day to be better, and dwell on all the things I wish I could have done all day.

APS has taken away the vibrant, happy person I used to be, it has taken away my hobbies and happiness, leaving me with my constant companion, APS! I cannot make plans with friends or family, I just don't know how I will feel that day. I can't seem to make some of them understand that I would have loved to have joined them, but couldn't. I have made the mistake of promising my girls that I would take them somewhere, but when the day came, I couldn't. I see the anger, frustration and sadness in their eyes, and I understand. That's when I feel most guilty – letting my family down.

I would do anything to feel better as I was all those years ago. To be able to get up and be spontaneous, and live the life I did would be a dream come true.

I am not asking for pity or sympathy. I am only asking for love, understanding and support. There are many days when I am in my "dark" place, as I call it, and would love for a hand to grab onto to pull me out of that dark abyss. Instead, I often receive criticism, anger and frustration. When I do have a "good" day, I make the best of it for my family, knowing that I will have to pay for overdoing it the next day. Even so, I cherish these days.

Hopefully, this will shed some insight on what our disease is like for the loved ones of APS sufferers. Maybe for a moment, I was able to have you look through their eyes. I realize having a loved one with any kind of illness impacts the entire family. For those of us who suffer from APS, we long to have the ties with those we care most about strengthened through love and concern and not eroded by frustration, neglect and denial. We all need to become a united family to battle this disease.

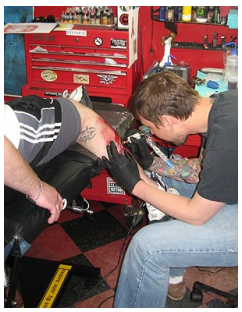
Inked for APS Awareness

Written by: Todd Ponagai

Tattoos usually hold a special meaning for the people who get them—they are forever after all.

A couple years ago, I got a tattoo of Frankenstein on the inside of my upper arm (let me say this right now, a tatt in your armpit hurts!). I got Frank because he was kept alive by electricity and I am being kept alive by the medications that I take.

I am an APS patient and I am on blood thinners. After I started taking warfarin I talked it over with my doctors and they gave me the ok to get another tattoo, just to make sure that the artist is aware I'm on blood thinners, to watch out for excessive bleeding, and to be sure that it heals well. Everything went smoothly with my Frank tattoo.



I was thinking about what my next tattoo should be and my wife totally vetoed every idea I had until I said, "What about an APS awareness ribbon?" She thought about it and finally agreed, but only if she could design it and it had no horror, no monsters, and no skulls included. I said ok and booked the artist.

It only took a couple hours to get the tattoo done, with several breaks to walk around and get the blood flowing, but I am now the proud owner of a burgundy awareness ribbon on my calf. I've already had a few people ask me what the ribbon is for, so everyday I have the opportunity to spread APS awareness.

There are many ways to spread APS awareness. Wear a burgundy ribbon on your lapel, or badge holder, use an APS awareness mug or mousepad at work, or wear an APS t-shirt. Whatever you do, spread awareness. Tell people about APS. Tell them your story. Together we can get the word out!

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APS Foundation of America, Inc.

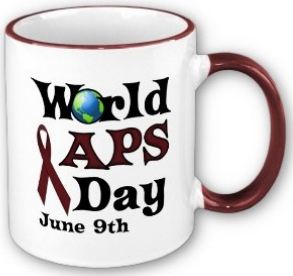
Our Mission Statement
Founded in June 2005, the APS Foundation of America, Inc. is dedicated to fostering and facilitating joint efforts in the areas of education, support, research, patient services and public awareness of Antiphospholipid Antibody Syndrome in an effective and ethical manner.

Sponsored by: **OPEN**

Shop CafePress & Zazzle
for APS Awareness Items!!

Our CafePress store is about to explode with over 15 brand new APS awareness designs which will be added just in time for APS Awareness Month! World APS Day items are now available! In May, we added over 15 new designs in our Lupus awareness store on CafePress.

We also opened our NEW Zazzle site in May! Zazzle is a little different than Cafepress and has really wide variety of items, including t-shirts for the entire family in sizes from infant to 6X! They also have a great variety of mugs and bags. Check our Zazzle store out and check back often, we will be adding items and designs to it soon! AND if downloaded the GoodSearch toolbar and buy from Zazzle, the APSFA will get an extra 10% per purchase!



http://www.cafepress.com/apsfoundation

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Items shown are all Zazzle items and will be available soon!