



ANTIPHOSPHO...WHAT?

APS Foundation of America, Inc. Newsletter

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APS Awareness Starts Here

Written by: Charles Strickler

What is APS? How do we increase awareness of APS? What research needs to be done to improve treatment options? These were some of the many questions discussed at the awareness and fundraising dinner that was hosted by me, my wife, Mary Strickler and our co-hosts, David and Kim Penberthy. We held the dinner May 17th, and it seemed more than appropriate to have such an event just prior to APS Awareness Month in June!

The initial inspiration for this awareness/fundraising event was sparked when we were discussing the challenges of having an unknown disease with our friends and neighbors the Penberthy's. Mary and I had never heard of antiphospholipid antibody syndrome until Kim and David started sharing their perspectives on Kim's experiences of living with APS. As I know all too well from my experience with Polycystic Kidney Disease (PKD), it's nice to know that you're not the only one dealing with a mysterious, often poorly understood disease. Such disorders are not only personal health problems, but they present challenges and concerns to our families and loved ones as well. Sharing our experiences lead to a unique opportunity to find ways to raise awareness and support to fund more APS research.

As we thought about hosting our event, we wanted to do more than just raise money. We wanted to ask friends and colleagues if they could join us in our efforts to put APS on the map. We wanted to host a group of people who could be educated, discuss

options, contribute ideas and in turn spread knowledge to others. Thus, we decided to invite several couples to dinner, including physicians, business people, and excellent fundraisers and creative folks (i.e, parents!). We also invited Dr. Thomas Ortel, an APSFA Medial Advisory Board Member, to attend as our special guest for this event. He presented an overview of APS and articulated a vast array of needs and challenges regarding APS, some that could



Invitations to the dinner were in the form of a hand-aid.

be accomplished with a few thousand dollars as well as those that would require very significant funding of millions of dollars. Overall, there were many unique and interesting ideas generated by all. One example was an idea to develop a documentary from a child's perspective (such as Kim and David's daughter, Morgan). This creative idea materialized when several people were discussing how a couple of seniors from a local high school won a national award for a documentary they produced. The numerous suggestions from this dinner for 20 people, were both stimulating and infectious. There was enthusiastic brainstorming, as well as expressions of genuine concern for people faced with the various challenges of APS. As the evening progressed, this diverse group of doctors and friends, many of whom had little prior knowledge of APS, learned more about the disease, the pressing research needs, and the many different ways they could help the efforts to increase awareness and search for better treatments. It was a very gratifying evening!



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



June is here already and we turn 3 years old this year. I must thank all of the hard working, dedicated volunteers and medical advisors helping to continue to make the APSFA a reality. Thank You for all that you have done!

The volunteers of the APSFA have been very busy raising awareness and raising money for awareness. One group of volunteers is actively pulling funds together to start a fund for research grants.

2007 as a whole proved to be a pretty good year for its second year. Here are some of the quick highlights: the APSFA home page benefited 51,483 people, made Press in 6 different media venues that we are aware of that benefited 1,000,000 people, and we attended several seminars that benefited about 5,000 people. As you can see we have are moving ahead by leaps and bounds. For the full year end report, please email the APSFA at apsfa@apsfa.org.

Our support forum is over 1,200 participants strong and have an average of 2,152 posts per month! It really is a very active support forum. If you haven't joined us there, you should!

The APSFA wants to encourage everyone to educate themselves about APS. This includes the products, services and devices that are promoted to you. Always read the fine print as what might be safe for someone else "may" not be safe for you. Always seek the advice of a trained physician in person before seeking any new treatment regarding your medical diagnosis or condition.

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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June is APS Awareness Month ~ Get In the Flow!

Written by: Tina Pohlman



As you may already know, June is APS Awareness Month.

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 on our website's media page at: <http://www.apsfa.org/media.htm>

Thanks to Bonnie Miller, DJ for WFLS 93.3 in Fredericksburg, VA, we have two radio air checks available. They are 30 and 60 seconds in length. We have converted them into videos for those of you who may want to include them in your blogs and social net-

working sites. You can find these air checks here: <http://youtube.com/APSFA>

We also ask that you contact your local radio station producers to see if they will run these on their airwaves. If you find they are interested and would like the final copy of these air checks please email us the name of producer(s) and their contact information of the station(s) you would like us to send these to for airing. Please contact us at: apsfa@apsfa.org. We will send them out the file directly.

Please keep an eye and ear out for our Press Releases during the month of June! If we made it into your local media, please drop us a line and let us know!

Big thanks also goes to Mark Hackley, country singer, who we featured in an article in

our last newsletter. Mark suffered and survived a PE and has decided to use his talent to create awareness for DVT/PE. Mark has generously agreed to donate 15% of his online music sales to the APSFA during the month of June! Please see his website www.markhackley.com or contact us for more information.



In addition, we have a couple more things in the hopper that we aren't at liberty to share, yet, but here is a hint: keep an eye on the TV as well.

The APSFA will be working extra hard 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!

APS Took My Breath Away

Written by: Franny Bishop

Isn't it nice to step outside and take a deep breath of fresh air? Afterwards I always feel rejuvenated, refreshed and ready to tackle my next task. My problem - I can't take a deep breath of fresh air!

Imagine wanting to step outside your house, ride in a car, take a shower, play with your kids **without** being attached to a tether, a rope, or a hose. For those of us on oxygen that is our dream. We are **always** attached to our oxygen because we need it to breathe. That oxygen tubing is part of our daily life.

Instead of just organizing medications for a trip, even a day trip, now I have to check oxygen tanks and supplies. Those trips to the pharmacy and doctors offices need to be well planned too, with the main question being, "Did you bring enough oxygen with you for the trip?"

My APS problems began with my lungs. For nearly one year I kept getting pneumonia, shortness of breath, and coughing up blood. **After** changing doctors I was immediately diagnosed with APS. What makes my case strange is that my lungs have taken the brunt of this disease. Yes, I've had a pulmonary embolism, a miscarriage, headaches, etc., but the APS has attacked my lungs which makes breathing and living

on a daily basis challenging.

We all know APS affects everyone differently. We all have our challenges in dealing with this disease and I just wanted to share a little bit of my journey with you.

I was diagnosed in July 2006 after an open lung biopsy. I did fine on medications for about one year, than Labor Day weekend 2007 symptoms started appearing again. Since that weekend I have had six hospital stays of seven or more days. The doctors were perplexed on how to treat me. I underwent several plasmapheresis treatments.

My plasmapheresis treatments were done in the hospital. I had one treatment a day for five straight days. The procedure was NOT painful or scary. I had this done four times, each time about one month apart. I would feel great, but the shortness of breath and coughing up blood would eventually return.

After that, the week before Christmas I tried IVIG treatments. Once again, these were not painful and were done in the chemotherapy rooms at the hospital as an outpatient. I had these treatments five days straight,

finishing up three days before Christmas. This seemed to hold me for about six weeks before my symptoms returned.



Two doctors, my pulmonologist and hematologist were coordinating my care and treatment options. Both are affiliated with Ohio State University in Columbus, Ohio and are fantastic caregivers. They both agreed to try an experimental treatment. So my next treatment included rituxan. This is NOT a proven drug for APS and it is VERY expensive. I received four infusions of rituxan, one a week for four weeks. I received my first infusion ten weeks ago and my IgG and IgM numbers are down to normal.

Now this may not last and I may end up back in the hospital with shortness of breath again. But, I am hoping and praying that these treatments have put me back on the road to normal. Or at least what us APSers can call "normal".

I am now planning a summer vacation with of course the approval of my doctors and I am making arrangements to get oxygen supplies lined up for a road trip to Florida!



Lupus Anticoagulant: Testing While on Anticoagulant Therapy: Can It Be Done?

Written by: Thomas L Ortel, MD, PhD

Testing for a lupus anticoagulant can be difficult, even under the best conditions. Testing for a lupus anticoagulant when a patient is taking an anticoagulant ('blood thinner'), such as warfarin (Coumadin®) or heparin, is even more difficult. Understanding how the testing is done helps to clarify the difficulties with diagnosing a lupus anticoagulant while taking these medicines, and may suggest approaches that can be used to identify an antiphospholipid antibody in a patient who is taking long-term anticoagulant therapy.

A lupus anticoagulant is identified by a certain pattern of abnormal results obtained when testing the clotting reactions on a patient's blood sample. Several steps are involved, including an initial screening test, followed by a step that mixes the patient's blood with blood from a normal donor (referred to as a 'mixing study'), and a step that adds in excessive phospholipids (to block, or 'drown out', the effect of the lupus anticoagulant). Phospholipids are critical for several steps to form a blood clot, and lupus anticoagulants (which are a type of antiphospholipid antibody) interfere with that process.

An important assumption that is made when interpreting test results for a lupus anticoagulant is that the blood clotting process is otherwise intact. In other words, if you could somehow remove the lupus anticoagulant, all of the blood clotting tests would come back 'normal'. Unfortunately, the medicines that we use to treat blood

clots in patients with antiphospholipid syndrome affect the blood clotting tests that are used to diagnose the lupus anticoagulant in the first place! Similarly, patients with severe liver disease have abnormal coagulation reactions that can complicate testing for a lupus anticoagulant.

For patients taking warfarin, the levels of several important clotting proteins in the blood are decreased by the medicine, and the clotting tests become prolonged (the INR gives us an idea of how prolonged these clotting test results are). Heparin and low-molecular weight heparin (such as Lovenox®) affect the blood differently, by interfering with, or inhibiting, some of these essential clotting reactions. Both types of medicines cause some of the screening tests for lupus anticoagulants to become abnormal, and, depending on the anticoagulant used, they can interfere with the mixing study as well as the step which adds excess phospholipids.

In the laboratory, certain tests for lupus anticoagulants can be used that are less affected by anticoagulants, but the doctor who actually orders the test frequently does not know how the laboratory is performing the test. Therefore, if the doctor does not know what type of testing the laboratory is performing, and the laboratory doesn't know if the patient is on an anticoagulant,

interpretation of the results can become very tricky, and, potentially, wrong.

In conclusion, it is optimal to test for a lupus anticoagulant when the patient is on no anticoagulant therapy. All of the test results can be interpreted more easily in that setting. Sometimes this can be difficult to

"Phospholipids are critical for several steps to form a blood clot, and lupus anticoagulants (which are a type of antiphospholipid antibody) interfere with that process."

arrange, however, and testing needs to be performed while the patient is still taking

anticoagulants. In this situation, the doctor needs to work carefully with the laboratory, to understand how the tests are being performed and to make sure that the results are interpreted correctly.

Of note, aspirin and clopidogrel (Plavix®) do not have this problem on testing for lupus anticoagulants. Also, testing for anticardiolipin antibodies and anti-beta-2-glycoprotein I antibodies (which are also antiphospholipid antibodies) does not depend on blood clotting reactions, and so these tests can be performed while the patient is on anticoagulant therapy.

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Energy Savings: An Open and Shut Case

Submitted by: Tina Pohlman

On cool days and nights, turn off your air conditioner and open your windows.

Install compact fluorescent (CFL) bulbs where you can. Over the life of one CFL bulb, you could save approximately \$40. Just a handful around the house and you could notice a difference in your energy bills. They cost a bit more, but you'll change them less often and they produce little or no heat.



open the oven door, the oven temperature can drop 25 degrees. Use the oven light or a timer to avoid wasting energy.

Close curtains and shades during the day to retain cool air and reduce the burden on your air conditioner.

Keep the doors inside your home open to improve air circulation and the efficiency of your cooling systems.

Keep your oven doors shut. Every time you

Run washing machines, dishwashers, and

clothes dryers with full loads. Get in the habit of running full loads to maximize energy use.

Set your refrigerator at the right temperature. Your refrigerator temperature should be set between 34 and 37 degrees and your freezer at 5 degrees. Not only are these the safest temperatures for food storage, but most refrigerators are manufactured to operate most efficiently at these settings.

Visit xcelenergy.com/energysavings for more tips and ideas.



General Management of Thromboses (Blood Clot) II—What Evidence is Available For You and Your Physician To Consider?

Written by: Gale McCarty, MD, FACP, FACR

Most rheumatologists approach anticoagulation (anti-blood clot) treatment for patients with antiphospholipid antibody syndrome (APS) based whether the thrombosis is at an arterial (art.) or venous (ven.) site. (Pregnancy is a special case not discussed further in this article). Hematologists approached the use of anticoagulation regimens differently, subsetting patients into 6 types of syndromes, and offered treatment guidelines for each group. However, as has been emphasized in Part 1 and other Newsletter articles, few large randomized controlled trials (RCTs, where patients got not treatment or a placebo) have occurred to verify these recommendations, whether designed/done by internists, neurologists, hematologists, rheumatologists, or any specialists. A general review for all re: APS and its various presentations, types, and issues can be found by accessing Bermas et al's '08 *UpToDate* data.

Why We Know What We Still Don't Know. Many factors contribute to the differences in how patients are treated: a) most importantly, the specific individual needs of any patient taking into account his/her other medical conditions that might affect treatment choices; b) recognition that the conditions under which patients have entered into RCTs or prospective (forward-looking)/retrospective (backward-looking) cohort studies of anticoagulation are not always equal, and c) the exact type of aPL antibodies by ELISA vs by LAC coagulation-based testing has implications in terms of levels, how constant they are, how frequently assessed in the studies, and *no one knows exact predictive values for any test for thrombosis*. As discussed in Part 1, systematic reviews and meta-analyses of studies themselves differ in methodology and even with strict rules, there may be difficulties in comparison across studies even when methods to assess data differences (heterogeneity) are applied...*the devil is in the details*. Many recommendations for treatment of common blood clots (deep vein thrombosis (DVT) or pulmonary emboli (PE) come from data in patients without APS, but are generally accepted treatments because they work in the common types of blood clots seen.

General Guidelines to Thrombosis Treatment With Various Types of Anticoagulation/Anti-Platelet Therapies. Table 1 presents general guidelines synthesized from standards of care in many sources (see References, especially Bick and Baker '08 for details).

Thrombosis Site:	Acute Rx:	Chronic Rx:
DVT +/- PE	Heparin/LMWH	Heparin/LMWH crossing over to Warfarin; INR 2-3; Anti-platelet Rx;
Coronary / Peripheral Art. Aortic/Carotid Art.	Heparin/LMWH	Heparin/LMWH crossing over to Warfarin, INR 2-3; Anti-platelet Rx (eg. low dose aspirin [LDA] or clopidogrel)
Retinal Art./Ven. Cerebrovascular	Anti-platelet Rx	Heparin/LMWH if Anti-platelet Rx fails; varies by site
Mixtures of Above Sites	Depends on site	As above, depending on site

The mainstays of treatment have involved anticoagulation as acute therapy with unfractionated heparin (Heparin) or low molecular weight heparin (LMWH) then the introduction of Warfarin while acute treatment is weaned off, when the target International Normalized

Ratio (INR), a measure of how "thinned" the blood is, is reached. In the mid '90s, the trend was an INR of 3 based on Khamashta's initial work, because at that time, that value represented the *best balance between preventing recurrent thromboses vs. major bleeding*. Treatment is usually continued, because the risks of recurrent (rec.) thrombosis in APS patients is high. Lim et al looked at RCTs and prospective cohort data on APS management in a systematic review (see Part 1) and made several recommendations:

- When compared with placebo or untreated controls, anticoagulation with moderate intensity Warfarin (INR 2-3) reduced the risk of recurrent venous thrombosis by 80-90%
- Additionally, Warfarin (INR 2-3) seemed to be effective in preventing recurrent arterial thrombosis
- High intensity Warfarin (INR >3) was not more effective than moderate intensity dosing.

Studies by Crowther et al '03 and Finazzi et al '05 represented some of the best data.

Ruiz-Istoraza, Hunt, and Khamashta's recent systematic review looked at how good treatment was at preventing 2nd clots and how safe treatment was for patients. Table 2 replots their summary data from 16 different types of studies with patient nos. from 15 to 720/ per study. (Note: these data are summaries and not segregated by clot site).

Treatment	No. of Pts w/ Rec. Thrombosis	Thrombosis Site	Major Bleeding	Minor Bleeding
No Rx	104	16 Art. 42 Ven.	-	-
LDA	27	10 Art. 2 Ven.	-	-
Warfarin				
INR>3	7	4 Art. 1 Ven.	20	49
INR<3	42	13 Art. 16 Ven.	5	19

Based on these results, the following recommendations were made;

- When a first venous thrombosis occurs in an APS patient, Warfarin (INR 2-3) is suggested long-term
- When rec. thrombosis and/or arterial events occur, Warfarin (INR >3) is suggested.
- When a patient has a venous thrombosis or stroke with a single pos. aPL test, repeat aPL testing for persistence of the aPL is recommended:
 - If aPL is not persistent, Warfarin (INR 2-3) is suggested for venous Thrombosis
 - If aPL is not persistent, LDA is suggested for stroke

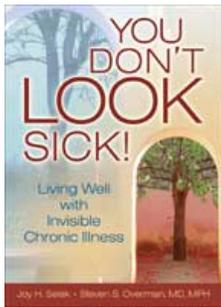
Cautions and Caveats-We Don't Know Everything Yet But We Are Trying. As always, the physician treating the individual APS patient

(Continued on page 7)



Book Review ~ *You Don't Look Sick: Living Well With Invisible Chronic Illness*

Written by: Tina Pohlman



You Don't Look Sick: Living Well With Invisible Chronic Illness (Paperback) by Joy H. Selak, Steven S. Overman; Published in 2005 by: Haworth Medical Press (March, 2005); ISBN: 0789024497

You Don't Look Sick! Living Well with Invisible Chronic Illness chronicles a patient's true-life stories and her physician's compassionate commentary. This warmhearted resource helps you focus on building a meaningful life that contains illness as opposed to a life of frustration and fear. Designed for patients at all stages of the chronic illness journey, this book is also illuminating for caregivers and loved ones.

My View:

Some of you may know that I have had

an experience this past month that has upset me quite a lot. I had an allied health worker ask me point blank "has anyone told you that you are a hypochondriac." It didn't really hit me until I started leaving the hospital. I had so many one liners it wasn't funny. Why I can't think of those when people say this insulting stuff to me, I don't know. But this day, I was crying by time I got home. I am used to the "you look so good" and "the now what is wrong" or "you are making mountains out of molehills" from family and friends but this one struck a nerve with me. So I decided to order this from Amazon.com for some insight.

This book stresses that you can live well, even with chronic illness. You just may need to change things a little bit. You probably will not be able to do what you did before but you can have a new level of you. I found myself shaking my head in agreement throughout most of the book. I was not alone in how I felt any longer.

The 10 take away points were to put yourself first; never, never, never give up; know who you are now, and let others know who you are now; enroll in the school of whatever works; make friends with fatigue; step out of the box; search for silver linings and avoid any medicine that will make you fat. As the co-author points out, you have to have some standards. The biggest ones for me, step out of the box and let others know who you are now. The rest of them, I was already doing in some sort of fashion.

The book does point out that many of these chronic illnesses do not have cures. Also chances are your doctor(s) are just as frustrated as you are.

This book may also be helpful for family members and friends who "don't get it". It also points out the battles we go through to get the health care that we need and what levels insurance companies will stoop to deny claims.

Overall, it was a good read. I give it 4/5 stars. ★★★★★

Genetics of Antiphospholipid Syndrome Study

Written by: Thomas L Ortel, MD PhD

A question that I am frequently asked by patients with antiphospholipid syndrome (APS) is whether it might also affect any of their family members. Other autoimmune disorders, such as lupus, have clearly been shown to have a genetic component, although the patterns of inheritance are complex. We have previously described several families in which more than one family member was affected with APS, and antiphospholipid antibodies are reported to occur more frequently in the family members of indi-

viduals with APS, lupus, or other autoimmune disorders.

We are currently recruiting patients with APS for a study investigating the genetics of the disorder. The "proband" (typically the patient) must have symptoms associated with the disorder (such as blood clots, or recurrent miscarriages) and the presence of the antibodies associated with the syndrome (for example, the lupus anticoagulant, or anticardiolipin antibodies). The "proband" also needs to have at least one or more family members affected with APS, or

one or more family members affected with another autoimmune disorder (for example, lupus, rheumatoid arthritis, multiple sclerosis, myasthenia gravis, etc.). We currently have participants enrolled from more than sixty families, and are looking for more!

To learn more about the study, please visit our Rare Thrombotic Diseases Consortium website (<http://rarediseasesnetwork.epi.usf.edu/rtdc/>) or ClinicalTrials.gov (<http://clinicaltrials.gov/>). Contact information for Dr. Ortel and colleagues working on this study is available at these two sites.





Elena's APS Story

Written by: Elena Gonzalez



Hello. My name is Elena, I too have APS. I'm originally from Los Angeles currently living in Fort Worth, TX. I was diagnosed with APS

in May of 2002 at age 22 after suffering a stroke which was caused by birth control pills I was taking for about 30 days. When I walked into the emergency room and explained my symptoms (disorientation, numbness on the left side), I was going to be sent home by the ER doctor who quickly diagnosed me with a panic attack and carpal tunnel. I asked her to call my doctor and ask for his opinion. He requested a CT Scan, after about an hour after the CT, the ER doctor walked into the room white as a ghost and said I had two blood clots on the right side of my brain. I thought I was going to die.

I was in the hospital for about a week because the doctors couldn't figure out why I had a stroke at such a young age. They weren't exactly sure if it was APS because I had never been pregnant or had a miscarriage before. After about two weeks I was finally diagnosed with APS by my internist and Neurologist, and was put on a combination of Coumadin and Plavix. I was told I would now have to be on Coumadin for the rest of my life and should speak with my doctor before I ever tried to get pregnant. I thought great I'm 22 and now need to take a stupid pill and have a blood test every week for some disease I know absolutely nothing about.

I fully recovered from my stroke. In late 2004 I moved back to Los Angeles to continue going to school. I was working and going to school full time. It was very stressful. In July of 2005 I felt sick for about a week, thought it was the flu but it turned out to be something else. One night I was so weak and was coughing up blood. My sister drove me to the hospital and it turns out I was having a

heart attack. I had several tests done and found that I must have had a blood clot but tests no longer showed anything and doctors said it must have dissolved on its own.

After a week in a hospital I was stabilized enough to have an angiogram of my heart. The test was to be performed at a different hospital. I had the worst headache ever the night before, so that morning I was still a little groggy and remember very little. Apparently the test went well, but by the time I made it back to the hospital I was at initially, I arrived unconscious and was in a coma for about a week due to hydrocephalus (water in the brain). The neurosurgeon told my family that I was a very sick girl and that it would be a miracle if I made it through this. I don't remember much, but I remember coming out of surgery and hearing the doctor say, *"Oh my god, I can't believe I just did that, this lady is very lucky, very sick, but very lucky."*

Lying in bed at the hospital for so long, I developed a blood clot in my right calf. It felt like my leg was so heavy and like it was about to burst open. It was so painful I wanted to rip all the IV's out of my arms and get out of the room to get someone's attention. I had emergency surgery and my vascular surgeon was able to save my leg. Subsequently my foot became gangrene. The plastic surgeon I was assigned gave up on my leg. He said I would never walk again and that there was nothing he could do and he recommended amputation.

My family and I were very adamant that I was going to keep my leg and together with my vascular surgeon we were able to convince the plastic surgeon to work on it. I was in so much pain that I was put on a morphine drip for a month. I later got a skin graft placed on my wound and it took a long time for it to completely heal.

I was finally able to go home in September 2005. I needed total care. I was going to be sent to a convalescent home, but my mother and my sister would not

allow it and took care of me. I honestly don't think I would be here if it wasn't for my family and for the wonderful doctors I had. I call them my angels. Every doctor I saw said I was a miracle and couldn't believe what I went through and that I came out of it *alive*. Even after a lot of physical therapy I wasn't able to really walk on my own until December of 2006. It has been years of doctor visits and lab visits almost every week. My medical record is the size of two phone books stacked together and I have the medical history of a 75 year old woman, even though I'm only 28.

I just recently moved back to Texas and am living with my parents again. I am now disabled due to Dilated Cardiomyopathy and CHF and still have several issues going on with my leg. But I am very thankful for my family, especially my mother who literally did not leave my bedside for a day. I still have the usual aches and pains, dizzy spells and brain fogs but I guess all that goes with the territory being a person with APS.

(Continued from page 5)

has to balance the wisdom of these guidelines (which are general guidelines and not mandates applicable to ALL patients) with the needs of his/her patient to find the best answer. Physicians are directed to please read these References to understand the caveats and critiques of systematic reviews/meta-analyses of studies.

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Warfarin and Menstruation

Written by: Gretchen Kunze, Pharm.D Candidate

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"For years I have experienced terrible menses. I am to the point where I cannot call my flow "heavy"...it is far beyond that...I am to the point where I almost cannot leave my house ten days of each month because of my "problem".⁹

This quote was taken from a 40 year old woman being treated with warfarin because of recurrent blood clots. This scenario may be all too common and a huge dilemma for pre-menopausal women taking warfarin.

Warfarin is used to treat or prevent blood clots from forming. Warfarin interferes with the body's natural coagulation factors making it less likely to clot. One of the contraindications to taking warfarin is in patients with hemorrhagic tendencies^{7,8}. This usually refers to people that have bleeding disorders or that participate in activities that may put them at risk for cuts, bruising, or injury, increasing their risk of bleeding. When an injury occurs, it is difficult to get the patient to stop bleeding because the body's clotting factors have been reduced. This may seem straight forward, but what about the thousands of ovulating women taking warfarin who experience menstruation on a monthly basis? We usually don't think of our periods as an "injury," so will warfarin really affect a woman's menstrual flow?

The menstrual cycle is a natural process and is regulated by different hormones. Each month, a woman's body prepares for fertilization and goes through many steps to achieve this. During ovulation, there is an increase in estrogen levels, which stimulates the cells lining the uterus to reproduce, therefore thickening the uterine walls. If the egg is not fertilized during this time, the thick lining sheds and sloughs off, resulting in menstruation^{5,8}. Although the female is actively bleeding, this is not because of an injury or an open wound. Regardless, warfarin has been shown to alter a woman's period.



Ever since warfarin has been introduced, there have been reports of women experiencing complications with their periods while taking this drug. Warfarin has the potential to increase the amount of bleeding during menses and possibly the number of days of your period^{6,10}. An increase in bleeding may also result in an increase in cramping, adding to the discomfort¹⁰. A study conducted in Sweden looked at the effects of oral anticoagulation treatment in 90 fertile women between the ages of 15 and 49 years. They reported significant increases in the average duration of their period from 5.6 to 6.1 days. As well as the number of women who experienced heavier flow from 44% to 71%. The number of women who had heavy menstrual bleeding increased from 18% to 30%.²

These factors can contribute to a decreased quality of life. One of the biggest things we try to accomplish as health care providers is improving a patient's quality of life.⁵ However, we are also obligated to prevent unnecessary harm, in this case the development or recurrence of blood clots. The use of warfarin in an ovulating woman may significantly decrease her quality of life during her period, but this burden is outweighed by the other possibility of developing a blood clot. None the less, efforts should be made to try and improve the patient's situation as much as possible.

If you are woman who is suffering from these complications, there are treatment options available to you. The biggest deciding factor of what option you choose is whether you want to continue to have children or not. If a woman decides she does not want to have children anymore, her treatment options include endometrial ablation or a hysterectomy. Endometrial ablation is a process where the lining of the uterus is burned out and destroyed, preventing further build up of the uterine lining. As a result, menstrual bleeding is prevented¹⁰. On the other hand, if a woman would like to have children in the future, she can choose hormone treatment to help decrease her symptoms. One of the more

common hormone treatments is the Mirena® intrauterine device (IUD) that releases low doses of progestin into the uterus continuously. This method helps to decrease the thickness of the lining of the uterus and eventually the bleeding should stop¹⁰. Oral progestins or oral estrogens are alternative options, however, the use of estrogens may increase the patients risk of clotting⁵ so they are not generally recommended in APS.

Patients on warfarin are instructed to tell their doctors if they are experiencing any signs and symptoms of bleeding. If a woman has an increase in her menstrual flow, she should report this change to her doctor as soon as possible. Even though an alteration in menstruation is common, reporting this problem may allow for earlier interventions and avoiding potential complications down the road.

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APS ~ Just A Part of Us (Todd's Story)

Written by: Heidi Ponagai, wife of Todd Ponagai

Four years ago if someone would have asked me what APS was I wouldn't have had a clue. But since my husband, Todd's, diagnosis, APS has been a part of our everyday lives. This is his story.

Everything started in 2000. Todd was 28 and had chest pains almost everyday. We were in the ER so much they knew us by name. They always did a chest x-ray, found nothing and would send him home with some Motrin. This went on for months until one day they heard something abnormal and found that he had fluid around his heart and both lungs. Todd was admitted for 8 days.

During this stay they did many tests which all came back normal, he was still having chest pains & pleurisy, and his lymph nodes became enlarged. They did a biopsy and he was diagnosed with CMV and sent home.

The chest pains never did go away and neither did the fluid around his lungs. In 2003 Todd was hospitalized again to have the fluid drained. During this stay in the hospital as well as the one in 2000 he was tested for Lupus. Both came back negative.

In August of 2004 Todd had pain in his calf that lasted for a few days. I dismissed it as a "charley horse", but he went to the ER and they found a DVT from his knee to his ankle. He was again admitted and was finally tested and diagnosed with APS. I honestly believe that the CMV in 2000 "triggered" his APS and that all of his problems between then and the DVT were APS related.

Since his APS diagnosis, Todd has had at least 20 TIA's and has also been diagnosed with a positive Lupus Anticoagulant, vertigo, Raynaud's, Sjogren's, Sticky Platelet Syndrome, anemia, osteopenia in his lumbar spine, and had a hole in his heart. In September, 2005 the migraines started and in 2006 he was diagnosed with 2 other clotting disorders, one that is inherited.

In April, 2006 he had his first TIA in a therapeutic INR range and in June, 2006 he had surgery at Children's Hospital in Detroit to patch the hole in his heart. The surgery went really well and his surgeon was awesome, however, his migraines increased in frequency and intensity after that surgery.

In July, 2006 he was scheduled for a non-APS surgery and it was cancelled due to an abnormal EKG. He was having bigeminy and

PVC's and PAC's. He was connected to a 48 hour heart monitor and was later put on medication for his racing heartbeat.

In August, 2006, he went through 4 Rituxan chemotherapy infusions in hopes that it would help his APS symptoms. His hematologist recommended it and thought that Todd would be a perfect candidate. Unfortunately we found out in October, 2006 that the Rituxan did not work as they had hoped for Todd. In fact, it made some of his numbers go up.

His INR was kept in the 3.0-3.5 range and we had a really hard time keeping him therapeutic. After months of problems with the anticoagulation clinic and a really scary false finger stick reading, he was put on Lovenox long term in 2007.

He went back to see a surgeon about the surgery he was supposed to have in 2006 and the surgeon will not perform the surgery because Todd is a high risk. This is not something that can be left alone and eventually he will need to have the surgery, so we're just going to have to find a surgeon who's willing to do it.

One good thing, if this can be called a good thing, about Todd is that he always tests positive for APS. His antibodies do not wane and wane like they do with some people. This is both a blessing and a curse, because although the disease is staying put, he always gets proper treatment which, unfortunately, is not the case for a lot of APS patients.

In May, 2008 Todd was approved for disability which will help us breathe easier as far as money issues go. In the past 4 years Todd has had 3 jobs and although things have been going well with his job right now, who knows when the next wave of APS issues will be coming.

APS is an invisible illness. I can't tell you how many times I've heard how "good" Todd looks. He may look "good," but he may have a killer migraine and the world is spinning. That's one of the harder things to deal with. No one can understand what he goes through, and although I've been there for the

nose bleeds, the breakdowns, the times where his eyesight was messed up, and the TIA's, not even I can fully understand what it's like to live with APS.

He's been diagnosed with depression and he's had some really rough times with it. I've sat up nights with him when he's had breakdowns. I've felt helpless because he's been so upset and there's really nothing I can do. I don't fully understand what he's going through and I never will.



Todd and Heidi with their dogs, Onyx and Topaz.

Todd went from working full time, living & enjoying life to ER visits, blood draws, tests and doctor appointments. He went from going out with friends to going to bed early because of the fatigue. He used to be a line cook in a restaurant, but he can't do that anymore because he

couldn't remember the orders. He has memory issues and brain fog and lately he'll forget a conversation he had 10 minutes ago if he doesn't write it down right away. The past few years have been rough and we've been through a lot. Todd has been through a lot.

People sometimes ask me how we cope with everything or how can I say to my supervisor at work, "I have to leave because my husband is having a mini stroke" without missing a beat. Well, it is what it is. We take one day at a time and deal with what that day brings us. It's kind of weird to say this, but the disease has brought us closer together. We don't sweat the small stuff, we try to enjoy each other and time spent together and we just live. Sure, there have been scary times, stressful times, long nights spent in the hospital, but it is what it is.

Thankfully we have the support of our families and close friends and have found comfort in sharing our experiences with other APS patients and caretakers through the APSFA's online support forum, APS Friends & Support. We also find that it helps us to help others with this disease through our volunteer work with the APSFA.

If I could pass on any advice to someone who's been newly diagnosed or who is a caretaker, I'd say this: learn as much as you can, ask questions, join a support group to talk to people who have been through what you're going through, find a doctor who you trust and who is willing to treat the patient and not the numbers or the disease, and finally, just live.

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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.

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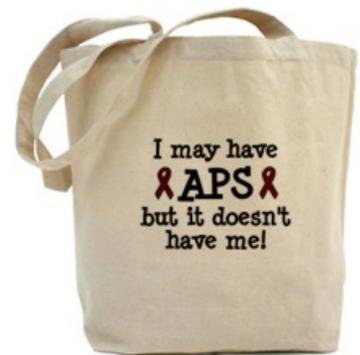


Have you browsed through our CafePress shop lately? ~ We have NEW Designs and Items!

We have been hard at work creating some new, fresh designs for our CafePress store! We now have items available for the following syndromes or diseases which are related to APS: Vertigo, Sjögren's, Raynaud's, Stroke, TIA, Heart Attack, MS, Migraines and Infant Loss. We have a few brand new lines coming out soon as well! Our CafePress 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 % 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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