



ANTIPHOSPHO...WHAT?

APS Foundation of America, Inc. Newsletter

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June is APS Awareness Month

Written by: Tina Pohlman & Heidi Ponagai

Antiphospholipid Antibody Syndrome (APS) is an autoimmune disorder in which the body recognizes certain normal components of blood and/or cell membranes as foreign substances and produces antibodies against them. Patients with these antibodies may experience blood clots, including heart attacks and strokes, and miscarriages. APS may occur in people with systemic lupus erythematosus, other autoimmune diseases, or in otherwise healthy individuals.¹

APS is also known as APLS, APLA, Hughes Syndrome or "Sticky Blood" in the United Kingdom.

With June being APS Awareness Month, this year we decided to do things just a little different. We are asking you to get involved with spreading awareness by sharing our newsletters, graphics, public service announcements and press releases on the social networking sites you belong to. I know many of us are on several of these addictive sites such as MySpace, Facebook and Twitter. If everyone posts one bulletin, shares one link, 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 will be available on the front page of our website as well as on our support forum by the beginning of June. We already have a number of blinkies and will be making a few 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 to share? It is all over the place! But here are good starting places for you to begin educating those around you and in your network: www.apsfa.org/media.htm and here: www.youtube.com/user/APSFA. You will also find photo albums that can be shared on

both our MySpace and Facebook Fan pages.

We realize that money is tight for many people so we haven't been actively soliciting for donations but we do ask you to check our new designs available in our Café Press store. 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 informational packets to those who request them free of charge.

Country singer, Mark Hackley who's story we have featured in a past newsletter has generously agreed again this year to donate 15% of his CD sales from the month of June to the APSFA. You can learn more about Mark by visiting his website: www.markhackley.com.

If you'd like to get involved and need help finding information, please contact us through the APSFA web site. 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's 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 **Get in the Know and Get in the Flow!**

References:

APS Foundation of America, Inc - www.apsfa.org

Are You Mapped?

Do you have a pin in our map?? If not, please add it. We are watching in amazement to see the clusters of APS people forming. Our Frappr map is located at: www.frappr.com/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!

Inside this issue:

June is APS Awareness Month	1
From the President	2
APSFA Board of Directors	2
Alison's APS Story	3
Talk About TIA Site	3
Hairloss and Warfarin	4
Book Review	4
Meal Supplement and Warfarin	5
"A Day" - Poem and Tribute	5
TIA's: Take immediate Action	6
Tips For the Newly Diagnosed	6
Coumadin or Generic Warfarin...	7
Living With APS	8
May is Lupus Awareness Month	9
CafePress	10

Letter from the President

Can you believe that June is almost here and that 2009 is already 1/2 over with? This year is FLYING by! It is mind blowing to think in June we will turn 4 years old. 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!



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 media page: www.apsfa.org/media.htm

Big thanks to Jeff Cecil from JMC Creative www.jmccreative.com, we have three 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 networking 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 the file directly.

Please also keep an eye and ear out for our Press Releases! If you see or hear any, let us know!

The APSFA will be out and 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.

2008 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 5 different media venues that we are aware of that benefited 6,000,000 people, and we attended a few seminars that benefited about 1,000 people. Our support forum is also going strong at over 1500 members with an average of over 1900 posts per month! As you can see we are moving ahead by leaps and bounds. For the full year end report, please email the APSFA at apsfa@apsfa.org.

The APS Foundation of America actively works with our medical advisors and their respective facilities to get the education out about APS. We have been contacting various newspapers and media sources to get the word out about APS and the foundation.

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 seek the advice of a trained physician in person before seeking any new treatment regarding your medical diagnosis or condition. Any information received from APS Foundation of America 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.

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Alison's APS Story—My Little Miracle

Written by: Alison Kavchok

My name is "Ali"; I'm a 27 year old Mother and Wife. My Husband and I started trying to conceive in June of 2005.

Like the typical first time Mom, I read the books, tracked my cycles, followed a pregnancy-friendly diet and found myself pregnant by Christmas. I was walking on air, confident that I would be holding a healthy baby in my arms nine months later. After confirming my pregnancy with my Doctor, I settled in to life as a Mom-to-be. By February I developed a little tummy which I proudly showed off, and discussed all of my pleasant symptoms with my friends.



Alison's newborn son, Mat, all wrapped up and on his way home from the hospital.

On February 14th, I started bleeding. I rushed to the Doctor, who performed an ultrasound and found a seemingly healthy 8 week old fetus accompanied by a strong heartbeat. I was provided a Rhogam shot since my blood type is B- and was sent on my way with the parting words "Everything is fine, these things are normal. Bye now!"

Within 4 hours, I had fully miscarried at home and was in the hospital all night, which was a mentally and physically excruciating experience. An ultrasound tech had the nerve to ask me "Are sure you were even pregnant?" I felt like a failure.

A few months later, we found ourselves pregnant again. Naively confident that this would work, I went about my daily routine only to find myself miscarrying again, albeit very early on. After changing Doctors, I started conferring with a Specialist regarding recurrent miscarriages. Detailed blood work was performed and the diagnosis of Antiphospholipid Antibody Syndrome (APS) and Polycystic Ovarian Syndrome (PCOS) was returned. I was prescribed Clomid during my next cycle, and yet again was pregnant.

Early on in the pregnancy I was prescribed Prometrium due to low progesterone levels, and was put on a regimen of Lovenox, baby aspirin and Metformin. I was to stop the Lovenox and start Heparin at 30 weeks.

I was 12 weeks along when again, the bleeding started. I rushed to my Specialist, panicking at the thought of miscarrying while on blood thinners and baby aspirin. My Doctor gently advised there was little he could do, I went home and waited. I nearly died that night. My husband loaded me in to the car and off to the hospital we went. I was provided morphine and examined. My blood pressure was 69/42 and I was in early shock from blood loss.

Not one to give up, I found myself pregnant again; and of course just like the last three times, I miscarried at 8 weeks.

I always considered 5 to be my lucky number, and the 5th time was a surprise. I was not confident. I prepared myself for the worst and told no one, even as my belly grew. When I finally did mention the pregnancy, I was met with concern and quiet ridicule. I was told that I should "give it a break" and adopt. My pregnancy was a dirty secret and I was going to fail as a Mother. The depression was crippling.

I started my cocktail of drugs; 10 weeks . . . 12 weeks . . . 14 weeks passed. Then the 16th week came and went - rather uneventfully! I was certain after all we'd been through, something horrendous would happen. We were considered high-risk and referred to Maternal Fetal Medicine at our local hospital. At twenty weeks I received an ultrasound confirming we were carrying a little boy. My textbook pregnancy continued, and we were blessed with Mat on November 21, 2007 who was born via c-section at

8lbs., 5ozs. And was 21 ½ " long. He's now 17 months old.

My Husband and I have decided to try for another child, and after three rounds of Follistim and two false positives, I am now 8 weeks pregnant. Again I am on Lovenox, baby aspirin, Metformin and Prometrium. So far, everything is fine.

If I could tell anyone *anything* regarding APS, it would be to accept, educate and celebrate your pregnancy. I've accepted APS; I've educated myself on it and have the utmost respect for those living with it, because I know there are people who suffer much more grave consequences of this condition than I. Pregnancy is a miracle, regardless of the outcome, and the body a vessel; you cannot change it.

Most of all, children are blessings, regardless of how you come about them.

Introducing a New Site To Learn About TIA

The National Stroke Association and Boehringer Ingelheim Pharmaceuticals Inc. are launching a new educational website,



Talk About TIA!, to raise awareness about transient ischemic attack (TIA). The site is the first complete, interactive online resource for people to learn about TIA and how to help reduce the risk of stroke. The site includes personal stories from TIA and stroke survivors. Visitors can send e-postcards to share what they learn about TIA and encourage those who might be at risk to speak with their doctors.

Visit www.TalkAboutTIA.com today.



Hairloss and Warfarin

Written by: Stephan Moll, MD; University of North Carolina School of Medicine

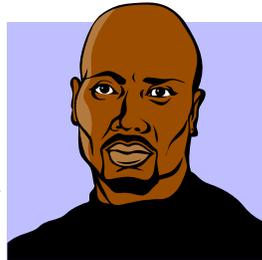
Hair loss is a known side effect of warfarin (Coumadin®, Jantoven®), but has hardly been studied (reference 1). Solid data on how frequently it occurs, on its time-course, and on treatments are, therefore, not available. Mild hair loss may be common, severe hair loss appears to be uncommon, complete hair loss has not been reported. In some patients hair loss occurs because of the patient's acute illness, i.e. the clotting event itself (and not because of initiation of warfarin therapy) and appears to start weeks to months after the acute event, and then slowly resolve. It can also be due to the underlying disorder, particularly autoimmune disorders, such as lupus erythematosus and antiphospholipid antibody syndrome.

The warfarin-associated hair loss may occur within weeks to months of starting warfarin, but has also been reported to occur after several years of therapy. In some patients it slows down in spite of continuation of warfarin. It has been found to be reversible, once warfarin is stopped.

If the hair loss is bothersome enough one

should discuss the use of a long-term low-molecular-weight-heparin (Lovenox®, Fragmin®, Innohep®) or Fondaparinux (Arixtra®) instead. However, low molecular weight heparins, as well as unfractionated heparin have also been reported to occasionally cause hairloss [references 2-6].

Little is known as to what to do to prevent the hair loss. There is a report in the medical literature that Coenzyme-Q10 (= ubiquinone), 30 mg per day, slowed and reversed the hair loss in 2 patients, in spite of continuation of coumadin® therapy [reference 7]. If a person starts Coenzyme Q10, he/she should get an INR checked 3-4 days later and again approximately 10 days later to make sure that Coenzyme Q10 does not influence the INR (an increase in INR was observed in one of the 2 patients reported). Other treatment interventions, such as Biotin or Zinc tablets, have not been studied. I am not aware of any data on whether the



drug Minoxidil helps with warfarin-associated hairloss.

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Modified from www.fvleiden.org/ask/22.html

Book Review: The Autoimmune Epidemic

23.5 million, or one in twelve, Americans suffer from an autoimmune disease, making them more prevalent than cancer or even heart disease.

Multiple Sclerosis, lupus, Type 1 diabetes, rheumatoid arthritis, and nearly a hundred other chronic autoimmune illnesses are part of this devastating epidemic, in which the human body, acting on misread signals, literally begins to destroy itself. Alarming, the occurrence of many of these diseases has more than doubled in the last three decades, signaling a disturbing trend that can be directly tied to environmental factors in modern life – including our daily exposure to a dizzying array of toxic chemicals and a societal shift to a diet full of processed foods.

In *The Autoimmune Epidemic: Bodies Gone Haywire in a World Out of Balance – and the Cutting Edge Science that Promises Hope* (Touchstone/Simon & Schuster, February 5, 2008; \$25.00/hardcover; 0-7432-7775-9), author and lecturer donna Jackson Nakazawa, herself afflicted with Guillain-Barré and other autoimmune disease, sounds a call to arms. Drawing upon up-to-the-minute studies from leading universities and hospitals, including Harvard University, Johns Hopkins Medical Institutions, and the

National Institute of Health, Nakazawa shows how “autogens” (heavy metals, toxins, pesticides, viruses, and everyday chemicals that can play a role in triggering autoimmunity) are wreaking havoc with the human immune system – and describes the revolutionary preventions, treatments, and cures emerging from top labs around the world.

This cutting edge research is accompanied by the heartbreaking stories of Nakazawa and other autoimmune sufferers. As their personal accounts show, anyone, is susceptible to autoimmune disease – from an athletic doctor in her forties to an entire neighborhood of teenage girls to very young children. However, surveys reveal that nine out of ten people cannot specifically name an autoimmune disease. More disturbingly, many general practitioners lack in-depth knowledge of these diseases and their diagnoses, and the average autoimmune disease patient sees six doctors – over an average of four years – before being diagnosed and treated correctly.

The Autoimmune Epidemic is a comprehensive study, alerting readers of the possible causes of autoimmune disease and offering hope for those who are already suffering. Nakazawa also provides practical advice about making the personal, political and economic choices that can help curb this epidemic before it is too late.





Meal Supplementation and Warfarin

Written by: Ashley Garcia & John Teel, Pharm D Candidates
University of Colorado at Denver, Denver School of Pharmacy
Reviewed by: Al Lodwick, RPh, MA

With summer just around the corner, many people want to shed those extra winter pounds. There are many options out there for weight loss such as exercise, dieting, or supplementation. People with APS need to be careful when considering losing weight. It is important to inform your healthcare provider about plans for weight loss. This includes how the weight will be lost as well as the amount of weight. People who are taking warfarin need to keep in mind that the amount of vitamin K in foods and dietary supplements. Fluctuations in dietary vitamin K intake can have a significant effect on anticoagulation in patients treated with warfarin.¹ Foods that contain vitamin K will interact with the main way in which the medication works. People may be at risk for a blood clot if the amount of vitamin K in their diet increases significantly. People taking warfarin and consuming changing amounts of vitamin K may have a variable weekly INR with potentially unstable anticoagulant outcomes.²



One option for weight loss that patients seem to use frequently is meal supplementation. Slim Fast is one of the meal supplements currently on the market. They have many flavor options and have shakes with extra protein. The purpose of these shakes is to replace a meal, not an addition to a meal. Slim Fast has anywhere from 190-220 calories per serving, depending on the product you chose to drink. There are 20 micrograms of Vitamin K in the product as well.³ Boost, another popular supplement, has 240 calories and 32 micrograms (40% of the recommended daily allowance) of Vitamin K.⁴ People on warfarin need to let their healthcare providers know that they are taking these meal supplements in order to correct for changes in INR. As with any other changes in diet, be sure that you are being consistent with the amount of Slim Fast you are taking in weekly. Because

there is around 25% of the recommended daily allowance of Vitamin K in each can, you need to get an updated INR to ensure there is not an interaction between the supplement and your warfarin dose.

Meal supplement shakes are used as a replacement for breakfast or lunch typically. The reason for that is the amount of calories and protein available in one can. To compare how many calories are in one of these supplements, a hamburger from McDonalds has 250 calories and a whopper junior with no mayo has 290 calories.⁵ A Slim Fast or Boost has almost as many calories as a whopper junior! This is why meal supplement shakes should not be used with a meal. The added calories will not help with weight loss. There are other snacks that have less calories that should be used when trying to lose weight.

These supplements are meant to be used as a meal replacement, not as an addition to a meal for nutrition or for weight loss. A well balanced diet of fruits, vegetables, and whole grains, as well as exercise is the best ways to stay healthy and get fit for summer. If Slim Fast or Boost is going to be used regularly, it is best if they take the place of a meal. An updated INR should also be taken a few days after starting these products due to the vitamin K content.

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A Day

Poem by: Theresa M Akard-Smock

*A day out of the madness of
illness,
Away from the shots and the pills,
When the sun rises as if on wings,
And shines as golden as
angels sing,
When I can look upon your
face so clearly,
And laugh without the hint of tears,
A prayer of thanks I give for such a
day and hold it dear,
Not spoiling the moment thinking
such days are too few,
That sorrow I condemn to the days
spent in the fight of dimming
Earthly light,
Sad they are so many.*

*As I survive each bad day, live
each good, and leave
behind either,
When the next has begun,
Celebrate with me every
hour we share,
Don't break my heart with talk of
years ahead while
Ignoring today so hard won.*



The author of this poem, Theresa, or Terri as many people knew her, lived and suffered with APS for many years.

We are publishing this poem in her memory. She lost her battle with APS on April 18, 2009 and is finally at peace.



TIA's: Take Immediate Action

Submitted by: Tina Pohlman

Patient to Patient: Tips for the Newly Diagnosed

Submitted by: Todd Ponagai

This Mini Stroke Can Be a Warning Sign

A transient ischemic attack (TIA) is an event sometimes called a mini-stroke, that produces stroke symptoms that last less than 24 hours before disappearing. While TIAs generally do not cause permanent brain damage, they are a serious warning sign of a stroke and should not be ignored.

What Causes TIA?

TIAs are usually caused by:

- Low blood flow at a narrow part of a major artery carrying blood to the brain, such as the carotid artery.
- A blood clot in another part of the body breaks off, travels to the brain and blocks a blood vessel in the brain.
- Narrowing of the smaller blood vessels in the brain blocking blood flow for a short period of time; usually caused by plaque (a fatty substance) build up.

What Happens When a TIA Occurs?

Blood vessels carry blood throughout the body. When a blood vessel in the brain becomes blocked for a short period of time, the blood flow to that area of the brain slows or even stops. This lack of blood and oxygen quite often lead to temporary symptoms such as slurred speech or blurred vision.



Symptoms of a TIA

They symptoms of a TIA and stroke are basically the same. Someone having a TIA or stroke might experience one or more of the following symptoms:

- Sudden numbness or weakness of the face, arm or leg, especially on one side of the body.
- Sudden confusion, trouble speaking or understanding.
- Sudden trouble seeing in one or both eyes.
- Sudden trouble walking, dizziness, loss of balance or coordination.

If you have any of these symptoms or see them in someone else, even for a short time, call 911 or get to the hospital fast. Treatment can be more helpful if given quickly. Every minute counts.

Managing TIA

The goal is to prevent future stroke. The medicine and therapy used depends on the exact cause of the TIA. In addition to lifestyle changes such as diet and exercise, your doctor might recommend:

- Drugs to treat high blood pressure, high cholesterol or heart disease.
- Medicines that help prevent blood clots from forming, reducing the risk of full-blown stroke.
- Surgeries to open the artery if a TIA is caused by a blockage, the main artery in the neck that supplies blood to the brain. These procedures are known as endarterectomy and stenting.

These changes can reduce your risk of further TIA or stroke. Ask your doctor about the best stroke prevention options for you, then take responsibility and enjoy a healthy lifestyle. Lifestyle adjustments you make today might reduce your stroke risk tomorrow.

Source: StrokeSmart™ March/April 2009 or www.stroke.org

- **Find a good Doctor who knows about APS or who is willing to learn about it.** You may need to change doctors. 
- **Learn as much as you can about APS.** The more you know about YOUR illness, the better you'll understand what signs to look for and what to tell doctors/nurses if ever needed.
- **Try to find websites that cite their information and are medically sound.** Doctors are more willing to accept information that has its sources cited, even better if they are medical journals. Highlight important sections that you want to point out to your care team.
- **Be prepared for your doctor's appointments.** Write your questions down and get answers to all of those questions.
- **Inform family and friends on the symptoms of the above and tell them what signs to look for.** This could also one day save your life!
- **Quit smoking.** If you smoke now, plan on quitting. If you don't smoke—don't start.
- **Watch your weight.** If you don't already, be sure to drink plenty of water, exercise and watch your weight.
- **Buy a Nurses Drug Book.** It will help you learn about different interactions with your medications.
- **Get your INR tested weekly.** Go on the same day every week if possible.
- **Know that you are not alone.** Your symptoms are real, and there are people who understand what you're going through.



Coumadin or Generic Warfarin, Is There a Difference?

Written by: Al Lodwick, RPh, MA

For more than forty years, Coumadin was the only brand of warfarin marketed in the United States. When generic equivalents of many drugs began coming to market in the 1970s, the technology did not exist to make a generic warfarin that was the equal of Coumadin. The various companies that owned the brand name Coumadin over the years needed to do little to market the product. Mostly they just proclaimed (rightly) that it was a drug that needed to be maintained in a narrow therapeutic range so there was no reason to even seek a generic equivalent. However, in the 1990s, when it became apparent that a generic that was as good as Coumadin, was likely to become a reality, DuPont Pharma vastly increased its sales and legal staffs and speakers bureau. The often repeated message was to not take a chance with a "Narrow Therapeutic Index" drug.

Trouble began to appear when the United States Food and Drug Administration in its "Orange Book" gave the generic products an AB equivalence rating. This meant that laboratory studies were unable to distinguish any difference between Coumadin and generics. Now there were differences of opinion between DuPont's people and laboratory staffs. What happened when there were head-to-head studies in real patients between the two products?

At a 1998 meeting of the American Society of Health-system Pharmacists, Swenson and Fundak on a group of 210 patients who were divided into two groups. One-half switched to generic warfarin and the others remained on Coumadin. The before-and-after differences in INR between the groups were small and of no clinical significance. This was of particular importance to the HMO doing the study since they were responsible for the entire health-care costs of the patients. Had there been any increase in laboratory testing, Emergency Room visits, etc it would have been to their economic disadvantage. By the time they published their report in 2000, the HMO had switched approximately 4,400 patients to generic warfarin with a 97% success rate. Neutel and Smith conducted another study about this same time that concluded that the products could be safely interchanged. This author reported on these two studies in a review article in 1999 and to date (3-15-03), I know of no challenge to their results.

In 2002, Milligan et al reported on another study of switching between products by an HMO. Their method was slightly different. They switched 182 people from Coumadin to generic warfarin. At then end of the study they collected data from eight months prior to the switch until ten months after the switch. The data included INR control, frequency of testing, the number of times that doses had to be changed, rate of thrombotic events and rate of hemorrhagic events. There were no statistically significant differences.

Witt et al reported on the largest warfarin switch study to date. At their HMO, 2,299 patients were followed after switching from Coumadin to generic. In the control period before the switch, 65.9% of the people had INRs in the therapeutic range. In the study period after the switch, 63.3% of the people had INRs in the therapeutic range. This was not considered a clinically significant difference. (By comparison, this Mr. Lodwick's clinic typically has about 60% of patients in the therapeutic range each month.) The authors conclude that supplemental INR monitoring is warranted when one

product is substituted for another to allow for timely detection of those patients who experience significant changes in anticoagulation response.

Are there any studies that show that Coumadin is better than generic warfarin? A search of Medline for articles published between January 1, 1996 to March 15, 2003 (limited to humans and with abstracts) containing the search words "warfarin AND generic" did not show any.

There are some case reports in the peer-reviewed literature uncovered by the above search described above. Wagner and Dent reported on a 61-year-old man switched from Coumadin to generic who suffered epistaxis. When the epistaxis occurred, the patient was on vacation. It is this authors impression that going on vacation and having houseguests are the two most common life-style changes leading to INRs out of range. Hope and Havrda reported on two cases of patients with INRs below the therapeutic range after switching to generic. There is no doubt that some patients will experience problems. Careful monitoring is justified.

Is there a difference between Coumadin and generic warfarin? DuPont agreed to a \$44.5 million settlement for overly aggressively marketing

Coumadin after the FDA found that there was generic equivalence. Henderson and Esham concluded, "misinformation and myths persists regarding the adequacy and proven reliability of the FDA's determination of bioequivalence of these products."

Here is the latest episode. Everyone using the national health service of Israel was required to switch from branded to the same generic version of warfarin. Halkin et al studied the warfarin dosing requirements of 975 people. They found that after the switch people required warfarin doses that averaged 26.5% higher. But there were no excess hospital admissions for these people. What was not given in the abstract of this article that I read was whether or not the generic and the brand were manufactured under the same set of standards. If they were, was there actual testing of the tablets, as they were marketed, to prove that they were meeting those standards?

The most definitive study that will ever be done on this took place in the province of Ontario, Canada and was reported by Paterson et al.. On June 7, 2001 everyone in the province taking Coumadin was switched to generic warfarin (except for about 10% of the people who had to pay 70% more to continue on the branded product). A study of 22,926 people on Coumadin during the forty months prior to the switch and 36,724 people in the nine months after the switch found no changes in the rate of INR testing, no changes in the rate of hospitalizations for major bleeding and no changes in the rate of hospitalizations for clotting-type strokes.

In the opinion of this editor, after the date of publication of the study by Paterson in 2006, anyone who claims that there is a difference between Coumadin and generic warfarin simply does not know what they are talking about.

References available: <http://www.warfarinfo.com/generic.htm>



Living with APS: Through a Husband's Eyes and Heart

Written by: Cris Gurley



My name is Cris Gurley, and my wife has APS. I'm still trying to learn how to

say it correctly, but I have found that knowing what it can do to someone you love is more important than being able to say it. My wife is Cindy Gurley. She is a greeter for the APS Forum and is the Secretary for the Foundation. She is known to most as "cyncris", but to me she is known as my inspiration and hero.

I met Cindy when she was still working a full time job, raising a son, and doing lots of volunteer work for her community. She was always involved in something and did what she could to help those around her in need. She is a very giving person and I'm still dealing with the fact that someone so young could be stricken with a disease that stops them dead in their tracks. It has taken away so many of the things that she used to enjoy in life, yet she smiles through all she's been through.

We got married in 1998 with dreams of having one child of our own. Cindy had no problem getting pregnant she just had problems carrying them. Each time we got pregnant we would get so excited only to be let down by a loss. The doctors where we lived at the time could really never give us a straight answer as to what was causing this. We decided that a baby was not in our future and decided to live life and change the things we could. So we packed up and moved to my old home town in Southeast Missouri.

Cindy had never lived anywhere but the city, so the adjustment from city girl to

country girl was hard on her. It wasn't long before she told me she was pregnant. Again, I was happy, but upset and worried at the same time. I did not want to see her go through another loss and I for certain did not want to see her risk her life to carry one full term. To be honest, I didn't really know how to feel. We decided to go with it and see where this road would lead this time. We found a Gyn/Ob that she just fell in love with. He did lots of blood work and when the labs came back it showed she had anticardiolipin antibodies. This doctor told her that this might have been the reason she kept miscarrying. He promised to watch her like a hawk and he stood by his words. He cried with us when he saw the heartbeat for the first time and he cried the day the heart stopped beating too. She didn't miscarry naturally so she had to have surgery. That was the saddest day of my life, she told me then - no more. She said she could not go through anymore sorrow. Cindy had her tubes tied shortly after that.

Cindy went on to have several DVTs, PE's, Heart attacks, strokes, seizures and other issues between the years of 2005 and 2008. I watched the life get sucked out of my wife by APS. The major stroke in May of 2008 was horrible. I looked down at my wife and saw her face but I didn't see Cindy...she wasn't there. It was as though I was staring at a body that had no life left in it. I was asked to give permission for the clot busting drug they use for strokes and I gave it. I was told it could possibly kill her, but I knew my wife would not want to remain the way she was at that moment. She could not talk, could not move her left side, and was so

scared. The drug worked! Within a day she was talking and recognizing those around her. She came home and went through intensive physical therapy. I was laid off at the time and I saw firsthand the way she fought to get her life back. There were days when she was so sick that the average person would have just laid in bed and said no to physical therapy, but she didn't...she got up and did what was asked of her and when they would say ok that is enough for today she would tell them no she wanted to go a little longer. I was finally getting a glimpse of the wife I know and love.

In November 2008 she had a heart attack and I had to give her CPR. That is the most horrible thing in the world to have to do. I never thought the ambulance would get here. She was in full cardiac arrest and it didn't take them long to sweep her off the floor and put her in the ambulance. She recovered, just as she has through everything else. Like I said she is my hero.

It's so important for family members and friends of patients with APS to realize that just because they look ok on the outside doesn't mean a thing about what is going on inside. I have almost lost my wife more times than I would like to count and I will always be here to support her. When she says she doesn't feel well I let her do what she needs to do. When she feels good I also let her do what she needs to, but sometimes she wants to do things that she doesn't need to be doing. As for me, I worry every time I leave the house. I wonder if she will have another stroke or heart attack while I'm gone. I worry that when I wake up in the morning will she be waking up or did she have a stroke in the middle of the night. I went to see a grief

(Continued on page 9)



May Is Lupus Awareness Month

Written by: Tina Pohlman

Lupus is a chronic autoimmune disease that leads to inflammation and tissue damage to virtually any organ in the body, including the joints, kidneys, heart, lungs, brain, blood or skin.

The immune system normally protects the body against viruses, bacteria, cancers and other undesirable invaders. In an autoimmune disease like lupus, the immune system loses its ability to tell the difference between the undesirable substances and its own cells and tissue. The immune system then makes antibodies directed against "self", which causes inflammation and damage to a person's tissues and organs.¹

The American College of Rheumatology's (ACR) current criteria for lupus, four are considered necessary to confirm the diagnosis with question, but the four *needn't be present simultaneously*. Some of the criteria are symptoms experienced by the patient or observable by both patient and physician; others must be determined by blood tests or other procedures.

Remember that this list, first drawn up more than three decades ago and already twice revised, is subject to future revision. Remember, too, that the criteria have been established chiefly to provide a common ground basis for

discussing the disease, not as a "test" the patient must pass. Many patients who unquestionably have lupus – perhaps half of all those who do – will never fully meet the ACR research-orientated criteria.²



Test Yourself for Lupus

- Have you ever had achy, painful and/or swollen joints for more than three months?
 - Have you ever had an unexplained fever over 100°F for more than a few days?
 - Have you ever experienced persistent, extreme fatigue/exhaustion and weakness for days or even weeks at a time, even after 6-8 hours of restful nighttime sleep?
 - Have you ever had a sensitivity to the sun where your skin "breaks out" after being in the sun (not a sunburn)?
 - Have you ever been told that you have a low blood count – anemia, low white cell count or low platelet count or other immunologic disruption – APS, positive ANA or anti-dsDNA?
- Have you even been told that you have protein in your urine?
 - Have you ever had chest pain on deep breathing for more than a few days (pleurisy)?
 - Do your fingers and/or toes become pale, numb or uncomfortable in the cold?
 - Have you ever had a prominent redness or color change on your face in the shape of a butterfly across the bridge or your nose or cheeks?
 - Have you ever had a seizure or convulsion?
 - Have you had sores in your mouth or nose that lasted for more than two weeks?

If you have answered "yes" to at least four of these questions, the APS Foundation of America suggests that you consult with your doctor and discuss any questions that you may have about lupus.

References:

1. Lupus Foundation of America – <http://www.lupus.org>
2. *Living with Lupus: The Complete Guide* – Second Edition, Revised and Updated by Sheldon Paul Blau, MD and Dodi Schultz; Published in 2004 by: Da Capo Press; ISBN: 0738209228

(Continued from page 8)

counselor to help me get past my fears. I was told that my fears were real and that I needed to focus on this moment and let the next moment take care of itself. I have to come grips with the fact that APS could take my wife at any moment. I want to stress that this is true with anyone that has a loved one with this condition. The biggest thing

they need in their lives is understanding and support from the ones they love.

I have found comfort in the support and knowledge offered by the APSFA. They have many kind people there who are willing to give a little extra. Tina has answered so many of my questions when I was lost and didn't know where to turn to. The APSFA helped me understand the things the doctors were talking about.

To get support for yourself if you are a family member or friend of someone with APS please go to apsfa.org to learn more about APS and what it can do to help your loved one. Their forum also can help you understand more about the daily living of APS patients. Do something to help find a cure for this ugly disease, donate to the APSFA or sponsor their webpage or forum. I'm positive if you contact Tina or Heidi they will lead you in the right direction.

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FIRST
CLASS
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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**

CafePress—APS Awareness Items

We have a number of new designs for APS Awareness available in our CafePress 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 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!!



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

