



ANTIPHOSPHO...WHAT?

APS Foundation of America, Inc. Newsletter
Volume 29 Spring 2015

June is APS Awareness Month and 2015 Marks the APSFA's 10 Year Anniversary!

We are thrilled to announce that this June is the APSFA's 10 year anniversary!

If you've been with us from the beginning, **THANK YOU** for believing in us enough to see our **dream** of an American non-profit foundation dedicated to bringing awareness to APS come to be a **reality**.

If you are newly diagnosed and have just found us, welcome, or if you've been here a while **THANK YOU for supporting us**. We truly appreciate each and every one of you

Awareness is important.

Research is important.

This is what we are about and this is where your donated dollars go towards.

If you were here for our 5 year anniversary, we held a special fundraiser and we will be holding another similar fundraiser this year.

HALF of the donations raised from our 10 year Anniversary Fundraiser will go to APS ACTION.



More details on that closer to JUNE.

We will also be taking our **#GOBURGUNDY** campaign to social media and we hope to color Facebook, Instagram, Pinterest, Twitter, Tumblr, etc **BURGUNDY!**

Let's make people take NOTICE!

We will be sharing graphics again on Facebook. **PLEASE** share these on your Facebook pages. We will also be sharing these throughout other social medias. Feel free to share as well.

If you wear **burgundy** - the official ribbon color for APS Awareness (along with a number of other clotting disorders!)- or if you wear dragonflies - the official 'mascot' of APS Awareness - post a photo using the hashtags **#GOBURGUNDY** and **#APSAWARENESS**

Together, we can make a difference and together we can bring awareness.

Stay tuned!! More exciting things to come! **#GOBURGUNDY**

#APSAIS10 !!!!

Be Social with Us!



Patient Stories & Articles Needed!

We are always 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.

If you have sent your story and haven't heard back from us, please contact us again.

Without your help our newsletter cannot be a success!

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Letter from the President

Where has the year gone? We are wrapping the books up now and starting our 10th year in service!



I must apologize for no June newsletter in 2014. We did have a great turn out with June APS awareness. Heidi made awesome graphics and to those who shared them, thank you!!! We saw them in places that actually surprised me.

I am still having serious problems with migraines. They are taking me out over 20 days out of the month. That doesn't leave me much room for much room for anything else. In the process, that has hurt our donations. So, this year has been a bad year for us in that aspect. However, I do thank the Kidd-Vogelpohl team for their fundraiser in loving memory of Jessica. We love all the awareness you guys do and look for something special in the mail, team Jessica! (Just remember it is me...I am slow but it is coming!)

We were able to donate \$1,250 to APS ACTION from the Giving Tree last year in memory of Silvia Pierangeli. We hope we are able to donate something this year.

Remember to sign up for the e-Newlster at <http://tinyurl.com/3rvb379>. We are planning on sending special articles out that will only be available to those that are on our email list or on Twitter.

We will also be discussing the support forum and disbanding it. If no one really wants to use it, why pay a monthly fee for it when that money can be used for other services. Unfortunately, due to security, we won't have another group on Facebook. We strive to keep our members' information private in our form and Facebook groups, even closed, are just not private enough. So we will put a poll on Facebook regarding the fate of our support forum.

We are also looking for more patient stories. Our newsletters are put together like a puzzle. So, if yours hasn't been used, not to worry, it will be, it just hasn't fit that spot yet. Those can be sent to articles@apsfa.org. If you want your photo added to the Faces of APS patient pictures, please send them to tina@apsfa.org.

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

Sincerely,

Tina Pohlman
President & Founder

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

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

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Weather Related Migraines

Written by: Stacey Chillemi
Submitted by: Tina Pohlman

Many people with migraines say that weather changes triggers headaches - especially extreme heat.

"Migraine is a prime example of a neurologic conditions with environmental triggers," says Orrin Devinsky, MD, a neurologist at New York University and Fellow of the American Academy of Neurology. "Foods are often considered the main trigger, but weather may be underappreciated factor. For many people with migraine, recognizing their own triggers - such as food or sleep deprivation - can be one of the more effective forms of prevention," he says.

According to a recent survey by the National Headache Foundation, specific triggers may include:

- Temperature changes
- High humidity
- High winds
- Stormy weather
- Extremely dry conditions
- Bright lights and sun glare
- Barometric pressure changes

Some experts suggest that people with frequent headaches, including migraine, have a lower threshold for pain or are more sensitive to changes in the environment, including weather. On the other hand, several objective studies (in which the patient is unaware of change in barometric pressure) do not show a consistent association between weather changes and migraine. (for a balance review of the topic, see "Migraine and the environment," Headache 2009 Jun; 49(6):941-51; <http://1.usa.gov/ZFo5NB>.)

KEEP A MIGRAINE DIARY



If you feel that weather might be one of your triggers, what can you do? This first step is to keep a migraine diary. Share this information with your neurologist. Below are several factors to include in your diary each time you experience a migraine:

- The date and time. When did the migraine begin, and when did it end?
- Where do you feel the pain. For example, is the pain shifting from one side of the head to the other, or does it affect the whole head?
- Changes in the weather. Was it especially hot or humid before your migraine started? Or especially cold and dry?
- What the pain feels like. Is it pounding or throbbing? On a scale of one to 10 (10 being the worst pain), how painful is the headache?
- The presence of any unusual symptoms before the pain starts. Some people experience unusual symptoms (also called an aura) up to 48 hours before a migraine starts. These may include nausea; drowsiness; irritability; sensitivity to light, sounds, or motion; visual disturbances such as seeing zigzag patterns or flashing lights; and others.

- What treatments you have tried in the past. Don't forget to include whether the treatment helped.

MANAGING WATHER-RELATED MIGRAINES

You may not be able to control the weather in the way you can avoid eating certain foods, but you can still plan around the weather to some degree.

"If a consistent pattern is identified where certain weather changes trigger migraines, then the person should take extra care during that time to get adequate sleep and avoid other triggers. The person should also keep medicine handy," Dr. Devinsky says.

For example, many people with migraine say that extreme heat or sun seems to trigger headaches. If that's true for you, try to limit your time outdoors during the hottest parts of the day. If you know you are going out in the heat, make sure to avoid other triggers. You may also want to consider wearing a sun hat and sunglasses when outside.

In addition, be sure you drink plenty of water. Dehydration may be a factor in migraines triggered by heat. But be careful about the beverages you choose: red wine and beer trigger migraines for some people.

Perhaps most importantly, keep your migraine medicine with you, especially if you are in weather conditions that seem to trigger headaches for you. And if you experience any of the early symptoms or warning signs of migraines (such as an aura) you may want to consider taking your migraine medication to help avoid or lessen the severity of headache.

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Lupus Awareness Month Facts - May, 2015

1. Lupus is an inflammatory, multisystem, autoimmune disease of unknown cause that may impact virtually any organ system in the body.
2. Lupus is an autoimmune disease - meaning the body's immune system becomes misdirected and attacks the very organs it was designed to protect.
3. Lupus is NOT contagious.
4. Lupus is not like or related to cancer or HIV/Aids.
5. Lupus is somewhat genetic - research suggests that genetics plays an important role, but it also shows that genes alone do not determine who gets lupus, and that other factors play a role.
6. Lupus can be a mild disease, a severe and life-threatening disease or anything in between.
7. Lupus is difficult to diagnose: more than half of the people with lupus suffer four or more years and visit 3 or more doctors before receiving a diagnosis.
8. Lupus has many different symptoms and affects each person differently.
9. Lupus is characterized by periods of illness, called flares, and periods of wellness, or remission.
10. Researchers do not know the cause of lupus.
11. 90% of people with lupus are women; however, anyone at any age can develop the disease.
12. Women of color are at greater risk for developing lupus - 2-3 times higher than Caucasian women.
13. Studies have confirmed that one virus, Epstein-Barr virus (EBV), which causes mononucleosis, is a cause of lupus in genetically susceptible people.
14. Lupus is often called "The Great Masquerader" because it can mimic viral syndromes, malignancies, allergic reactions, stress and other disorders.
15. Initial symptoms for lupus may be non-specific: fatigue, achiness, stiffness, low grade fevers, swollen lymph nodes or rashes.
16. Lupus symptoms may develop slowly or suddenly.
17. The range and effectiveness of treatments for lupus have increased dramatically in recent decades, giving doctors more choices in how to manage the disease.
18. Clinical studies have found that continuous treatment for lupus with antimalarials may prevent flares from recurring.
19. Research on work loss associated with lupus estimated that almost 3/4 of the study's participants would stop working before the usual age of retirement.
20. Learning to recognize the warning signs of a flare can help the patient take steps to ward it off or reduce its intensity.
21. People with lupus should receive regular health care, instead of seeking help only when symptoms worsen.
22. If new lupus symptoms are identified early, treatments may be more effective.
23. Men and women with lupus need to have their blood pressure and cholesterol checked on a regular basis.
24. People with lupus are at increased risk of premature cardiovascular disease.
25. Warning signs of a lupus flare: increased fatigue, pain, rash, fever, abdominal discomfort, headache and dizziness.
26. Participating in a lupus support group can provide emotional help, boost self-esteem and morale, and help develop or improve coping skills.
27. One of the primary goals of wellness for people with lupus is coping with the stress of having a chronic disorder.
28. Although pregnancy in women with lupus is considered high risk, most women with lupus carry their babies safely to the end of their pregnancy.
29. Approximately 40% of people with lupus will develop kidney disease (nephritis).
30. The annual economic impact of lupus is estimated at more than \$31 billion for direct and indirect costs in the US alone.
31. At present, there is no cure for lupus. However, lupus can be effectively treated, and most people with the disease can lead active, healthy lives.





A Mother's Story

Written by: Barbara Buchanan

It is sad to us, but it is also very comforting to us to know that all of you who are reading our story understand and have walked this same APS road. It makes us family!

Will was our first child, born in 1981. In 1982, when Will was nine months old, I took him to the doctor for a regular check up. Little



Barbara and Will

did I know the world we were about to enter. The doctor found an enlarged liver and spleen, and he immediately sent us to be tested for leukemia. There was no leukemia. We were then sent to Johns Hopkins Hospital for two weeks, where Will underwent every test known to man to try to discover what was wrong. We left Johns Hopkins at the end of those long, difficult days with no answers. His doctor told us that we would need to come back for another appointment to have a liver biopsy done ~ which also showed no reason for the spleen and liver to keep growing and growing. They decided to remove Will's spleen when he turned three, cautioning us to be sure he did not fall until then because his spleen was now thirty-three times larger than

normal. By the time he turned three, Will spent most of his days sleeping and lying around. When they removed his spleen, they discovered he had clotted off his splenic vein and had grown two smaller spleens to try to reroute the blood flow. The doctors believed it to be a once-in-a-lifetime happening.

For the next thirteen years, Will did just fine. When he was sixteen in 1997, Will's dad turned forty. At the surprise fortieth birthday party, Will was the surprise. Just as people began coming downstairs for the party, Will began vomiting massive amounts of blood and clots. Thankfully, EMTs responded quickly, and he was ambulated to our hospital in Dover, Delaware and then airlifted to Johns Hopkins hospital in Baltimore. His body had clotted off the portal vein which empties the blood from the liver. During the two weeks we were there, the doctors stabilized Will, found the clot, completed surgery to reroute the blood flow around the clotted area to the vena cava, and did lots of testing to discover what was happening. There were still no answers, but the doctors were very concerned that

now that it had happened twice, we would need to be very watchful.

Like many others who have APS, Will entered a period of depression. He was not able to do the things he had always wanted to. He didn't have the energy to pursue them or the physical health to do so.

In 2003, the family moved down to Mississippi, and Will chose to stay in Delaware. A couple of years later, he moved down and joined us.

May 25, 2007, while the wildfires were burning in Georgia and the smoke was drifting across to Mississippi, Will began having difficulty catching his breath and sleeping. I would wake up in the morning and find him sleeping in the living room recliner. We thought it might be asthma, since two of his siblings have asthma and off he went to the family doctor. The family doctor told Will that his heart was the size of a football, and he was in congestive heart failure. His mitral valve was not functioning.

We immediately went into survival mode again. Will was sent to a wonderful heart doctor, and after much testing and planning, his mitral valve was replaced with a metal one on July 5th, 2007. The surgeon said that Will had to have had rheumatic fever as a child, but I knew he

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Istanbul, Turkey: Host of the Next International Congress on Antiphospholipid Antibodies

Written by: Doruk Erkan, MD, MPH

15th www.apsistanbul2016.org
International Congress on
Antiphospholipid Antibodies
Istanbul, Turkey • September 21-24, 2016

The International Congress on Antiphospholipid Antibodies (aPL) is held every three years to discuss the recent advances and future directions in Antiphospholipid Antibodies (aPL) and Antiphospholipid Syndrome (APS). During the 14th Congress in Rio de Janeiro, Brazil in September 2013, Dr. Doruk Erkan, Associate Attending Rheumatologist at the Hospital for Special Surgery and Associate Professor of Medicine at Weill Cornell Medical College, was elected to host the next meeting in Istanbul, Turkey in September 2016 (www.apsistanbul2016.org).

Traditionally, the International Congress on aPL has been a venue for scientists and clinicians from multiple disciplines to discuss the most recent innovative and important research with the goal of improving our understanding of the syndrome, prioritizing research questions, and setting a roadmap for future research. Since the description of the syndrome in early 1980s, 14 International Congresses have contributed to: the description of the clinical phenomena of APS; the definition of the classification criteria; the understanding the mechanisms of aPL-related events; the description of the clinical problems other than blood clots; the creation of AntiPhospholipid Syndrome Alliance for Clinical Trials and InternatiOnal Networking (APS ACTION) (www.apsaction.org), and the exploration of new mechanisms and treatments. The field still needs more robust clinical trials, better risk prediction, and precisely targeted therapies.



The 15th International Congress on aPL will be an important platform for the discussion of the new mechanisms of aPL, evaluation of ongoing and organization of future clinical trials, including new treatments, and strengthening of established and creation of new international collaborations for both basic and clinical research in this field. The Congress will cover a very comprehensive program including: evidence-based state-of-the-art presentations from internationally recognized physicians and scientists; Task Force discussions and presentations covering the controversial aspects of diagnosis and management; keynote lectures; oral and poster submitted abstract presentations; and meet the professor sessions. The meeting will also produce a “state-of-the-art APS book”.

In addition, patient education workshops, guided by leaders in the field, will be included in the congress. These small sessions will provide an opportunity for patients to consult with highly respected professionals who have expertise in a particular area such as obstetric APS, thrombotic APS, and others. Thus patients are also welcome to join the meeting; further information will be announced in the future.

Turkey is centrally located at the crossroads of continents with 12,500 years of history. Istanbul is a city where two continents merge and where history is combined with modern life. The hope is that the 15th International Congress on aPL will similarly bring together rheumatologists, hematologists, thrombosis specialists, obstetricians, neurologists, immunologists, internists,

and all others researchers and specialists interested in aPL/APS to advance the field.

For more information about the meeting, you can visit www.apsistanbul2016.org or e-mail Joann Vega (vegaj@hss.edu).



An Atypical Antiphospholipid Antibody Story

Written by: Susan Reardon

I think my story is atypical of what I read about folks who have APS. For the longest time that caused me to think my condition wasn't really APS. I've been diagnosed for 11 years, and I now see how it's affected me years before that.



Susan and her daughter after a 5Krun/walk.

I'm fortunate to have had a primary care doc who would not give up and a supportive husband who wanted me to feel better.

Antiphospholipid Antibody Syndrome mostly affects me through symptoms. I've had clotting events, but it's the cluster of symptoms that truly affected my day to day living for 2 years. I was tired, really, really tired, had all over pain, intermittent vision loss and a hefty dose of cognitive confusion.

Like many of you, I was checked for Lupus, and MS. For lack of a diagnosis I was diagnosed with Fibromyalgia. The only thing it didn't really address was my vision loss.

I've been blind in my left eye since I was 8 years old. The fact that I was having intermittent vision loss in my right eye was concerning to my husband and my doctors, however I was done. I just couldn't see one more specialist. My primary care doc encouraged me to see a neuro ophthalmologist. Turns out it was the same one I saw when I was 8 years old. Although my eye health was fine, he wondered about low blood flow. That brought me to my (now hero!) hematologist who was able to find the root of all my challenges.

Eleven years later I feel great. I still have times of flares which are discouraging, but I bounce back within weeks. For 11 years I have given myself anticoagulant injections; sometimes 2x daily, sometimes daily, and currently every other day. Sure, there are risks and things to be careful with, but my philosophy is that we all have challenges. I'm fortunate that this major challenge was diagnosed and I'm healthy overall!

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MANAGINE MIGRAINES IN GENERAL

Whatever your specific triggers, the following steps will help your manage your migraines.

- Practice good sleep hygiene. Make sure you get enough sleep and try to fall asleep around the same time each night. Interruptions in your sleep schedule - such as getting to much or too little sleep - can trigger migraines in some people.
- Drink plenty of water. Eating regular meals and drinking enough water can help prevent migraines caused by a drop in blood sugar or dehydration. A common recommendation is to drink six or eight 8-ounce glasses of water every day. However, some adults may need more, depending on how much

more they exercise, for example.

- Be careful with coffee. Although caffeine can provide migraine relief (it's a major ingredient in many headache medications), too much can cause migraines. Caffeine can be found in chocolate and cocoa; beverages such as coffee, tea, and colas; and certain medications.
- Limit alcohol. Blood flow to our brain increases when you drink alcohol. red wine in particular triggers migraines in many people.
- Watch what you eat. Many foods can trigger migraines. A few of the more common ones include peanuts, peanut butter, other nuts and seeds, chocolate, and foods containing tyramine, such as aged cheeses and cured meats.



- Exercise regularly. Research has shown that regularly, moderate aerobic exercise may reduce the severity, duration, and number of migraines in many people. Regular exercise also helps control stress, another migraine trigger.
- Limit stress. Take time each day to relax. For example, listen to soothing music, take walks, meditate, or do yoga.

Go to aan.com/guidelines to read the American Academy of Neurology's most recent guideline on migraine prevention (published in 2012); to read the patient summary for the guideline (in English and Spanish) go to <http://bit.ly/10xuya> and go to <http://bit.ly/xvm4th> to access to the collection Neurology Now articles on migraine and headache.

Source and © of: NeurologyNow June/July 2013



Caregiving and Work: Tips for Tackling Two Jobs at Once

Written by: LeAnn Thieman
Submitted by: Heidi Ponagai

Are you one of the 54 million Americans who care for a family member? One of the 20-50 percent of employees who tend to a loved one before going to work, then return to care again after a long hard day on the job?



Feeling torn between both “jobs” and trying to perform well at each causes so much stress that working caregivers are often plagued with more mistakes, conflicts, and stress-related illnesses. These simple tips will help ease that stress:

Talk to Your Employer Honestly: Tell your supervisor about your caregiving demands at home. Make an appointment to discuss this at a time when you are better rested and feeling your strongest so you can state the situation in a professional, emotionally-controlled manner. Don't offer excuses, but instead reasons for changes he or she may note in your attendance, work schedule or attitude. Explain why you may need to decline additional hours, a promotion or transfer. Reassure him or her that you are committed to the company and its peak performance and will remain accountable to your duties.

Ask For What You Need: Once you've reinforced the above commitment, your employers will be more receptive to ideas that make the workplace and schedule more manageable for you. Come prepared with suggestions that will help—coming to work early, staying late or working from home; taking longer lunch hours to check on your loved one; make personal phone calls (or even take a nap). Brainstorm with him or her about other workable options. Often employers allow flexibility in the use of comp time, sick days and vacations. In many organizations fellow employees are allowed to donate accrued time off to help a caregiver during a crisis period.

Take Care of Yourself: Caregivers have higher than normal incidents of illness—those taking care of someone with a chronic illness have a 63 percent chance of dying early; another 63 percent say depression is their most common emotion. Caregivers often become so depleted they cannot maintain the stamina to continue caring for another. Therefore, you must take time daily to nurture yourself physically, mentally and spiritually.

- **Physically:** Eat well-balanced meals on a regular schedule. Take a daily multivitamin. Exercise regularly, even if it's simply taking a walk. As difficult as it may be, strive for a minimum of seven to eight hours of sleep a night and nap when possible. Get regular medical checkups and treatments of aches and pains before they turn into something more serious.
- **Mentally:** Pay attention to your own feelings and emotions and seek counseling if needed. While it's impossible to always leave the stress and heartache in the parking lot, try to keep emotions in check at work. Vent feelings to trusted family members or friends, not coworkers. Schedule time for yourself. Use relaxation or stress management techniques such as meditation, visualization, biofeedback and yoga. Stay actively involved with friends and hobbies. Create a support network and/or join a support group.
- **Spiritually:** Take time, even as little as 15 minutes per day, for prayer or meditation. Read or subscribe to inspirational magazines or books to uplift your spirits. Seek the counsel of a minister or religious leader you trust and respect.

Seek Support: Ask for help. Friends, family, and church groups are often eager to assist and are only waiting to be asked and directed. Find respite care so you can regularly take time out for yourself. There are countless community, state and national resources to support you not only at work, but at home as well. The National Family Caregiver's Associ-

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What is the Controversy Over Xarelto?

The controversy over Xarelto stems from its potentially severe side effects.

Some important points to consider before trying Xarelto.



- ➔ The FDA has challenged several of Xarelto's claims and advertising tactics.¹
- ➔ Xarelto is reported as safe and effective, but one side effect is an increased the risk of uncontrollable bleeds.²
- ➔ If severe bleeding occurs as a side effect of Xarelto use, it cannot be effectively counteracted because no antidote exists yet.² In contrast, warfarin can be counteracted with vitamin K or plasma products.³
- ➔ The FDA's 2011 approval of Xarelto for reducing the risk of stroke in people with NVAf was accompanied by a number of concerns, as noted during the FDA's Advisory Committee meeting and in their evaluation <http://www.fda.gov/downloads/AdvisoryCommittees/CommitteesMeetingMaterials/Drugs/CardiovascularandRenalDrugsAdvisoryCommittee/UCM278480.pdf> of the pivotal ROCKET-AF trial for NVAf.⁴
- ➔ In 2014, the Institute for Safe Medicine Practices issued a report ranking Xarelto as 10th among the most frequently named suspect drugs in reports of problems submitted to the FDA during the first full year the medication was on the market.⁵
- ➔ Notably, Pradaxa had made that list a year before.⁶ The FDA has been concerned about bleeding ever since Pradaxa was FDA approved as the first-in-class Factor Xa inhibitor. The concerns appear to be warranted—the incidences of bleeding are increasing as this new class of drugs is being prescribed more frequently. <http://www.recallcenter.com/xarelto-uses-expanding-despite-deadly-side-effects>
- ➔ The FDA rejected Bayer's latest application to approve Xarelto for preventing recurrent cardiovascular events after Acute Coronary Syndrome (ACS, a term describing any sudden interruption to the heart muscle's blood supply).⁷
- ➔ This was the FDA's second denial for this indication. Interestingly, no additional trials had been conducted since the FDA's first rejection for this indication.⁷ Though Xarelto's "new" proposed use was for dis-

crete, short-term (90-day) therapy instead of chronic (long-term) treatment, missing data and lack of statistical power once again were cited as reasons for an overwhelming "no" from the FDA. Interestingly, the 2012 article <http://www.ncbi.nlm.nih.gov/pubmed/22077192> describing these data mentions previous trials that yielded less favorable results, but explained the difference by saying Xarelto's trial was more careful in its patient selection.⁸ Undeterred, Johnson & Johnson has planned two new global clinical trials, to try to prove that long-term low-dose Xarelto can prevent secondary cardiovascular events in patients with ACS.⁹

- ➔ Boehringer Ingelheim recently agreed to pay \$650 million to settle more than 4,000 Pradaxa (dabigatran) lawsuits raising allegations of uncontrolled bleeding after taking that drug.¹⁰
- ➔ Not surprisingly, product liability attorneys are reviewing potential lawsuits regarding Xarelto being linked to wrongful death from brain hemorrhage, hemorrhagic stroke and other types of internal bleeding.

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Overall Source: American Recall Center



(Continued from page 5)

had never been diagnosed with anything like that! Just before the surgery, the doctor told Will and me that there was a line. Will had crossed the line, and the doctor was not sure that he would be okay, but he was going to try his very best. Thankfully, the new metal valve worked well for him. Again, we moved through depression and back toward life.

Will, of course, was put on Coumadin. The only problems he had were when the INRs were not quite right. He had a mini-stroke the next spring due to the INR levels. Then things settled down again for several years until he had a rhythm problem ~ atrial fibrillation at over 200 beats per minute. It

was during this time in 2011 that the emergency room doctor asked a hematologist to come see Will, and the new doctor ordered a multitude of tests. One of the tests, of course, was for APS. After twenty-nine years, we finally had a diagnosis! It was primary Antiphospholipid Antibody Syndrome.

Since that point in time, we have been managing the disease that finally has a name. In January 2014, Will had a stroke in his left temporal



lobe. It has affected his speech and his walking (both are slowly getting better!), and still causes him to be disoriented at times. He is finding things he can do around our house and the property (raising chickens is his pet project right now!) as he is

not able to work or drive any longer. I am so proud of his outlook on life, of his persistence in finding things that make him happy, and the major part he plays in our family as a favorite uncle to his six nieces and nephews.

Note from APSFA: We hope to bring you Will's story in his own words in the next newsletter!!

Do You Want To Share Your APS Story?

If you have read the entire newsletter to this point, then you've just finished reading an inspirational patient story about Will who has been living with APS for the majority of his young life and you also read Susan's atypical APS patient story.



The founders and most of the board members of the APSFA have APS or have loved ones who have APS. Each one of us have been through the trials of being diagnosed, getting treatment, seeing multiple doctors, researching the disease, and needing support.

We have found comfort in sharing our stories with other APS patients in hopes that what we have gone through may help them to now go through the same. This is why we always include at least two patient stories in our newsletters.

These are the stories written for other APS patients, by APS patients to assure them that they are not alone in this diagnosis; their fear and their confusion in the disease is valid.

In order for your story to be featured, please follow the guidelines below:

- Send your story to articles@apsfa.org
- Stories should be approximately 500-750 words long and written at a 5th-8th grade reading level
- Please include a title to your story (if it is "My APS Story" we will commonly rename it to "Name's APS Story")
- Please try to include a photo

We do accept longer and shorter patient stories and will print them. Sometimes longer articles are more difficult to work in the space available and we don't like to edit the content of the articles too much. It really depends.

If you have submitted an article and we have not printed it yet, please email heidi@apsfa.org and I will look into it for you.



(Continued from page 8)

ation (www.nfcacares.org) is an excellent start in accessing this information. Another great resource is the Local Office on Aging (www.loaa.org). With the passage of the National Family Caregiver Support Program in 2000, all LOAs have a mandate to address the needs of family caregivers.

Finally, if needed, you may be able to utilize The Family Medical Leave Act (FMLA), a national policy that guarantees covered employees 12 weeks of unpaid leave each year to care for a newborn baby, a newly adopted child, a seriously

ill family member or to recover from their own serious health condition while ensuring their job security. Each state has different regulations. To learn about yours, call your state legislator.

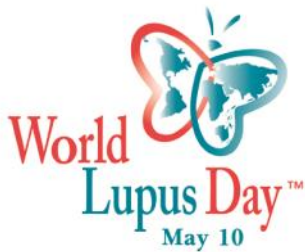
Following these tips will help you better tend to your job, your loved one, and yes, yourself.

Article is © the author and was originally posted on StrokeSmart website at the following website:

<http://www.strokesmart.org/new?id=84>

About the author: LeAnn Thieman LPN, CSP, CPAE is coauthor of Chicken Soup for the Caregiver's Soul, plus 11 more Chicken Soup books and Balancing Life in Your "War Zones," A Guide to Physical, Mental and Spiritual Health. She is a nationally acclaimed motivational speaker and inductee in the Speaker Hall of Fame. To learn more about caring for the caregiver, her books or presentations see www.LeAnnThieman.com.

World Lupus Day ~ Sunday, May 10th



World Lupus Day increases awareness of lupus and helps gather support for the more than 5 million people affected by this condition worldwide.

Lupus is a serious, life-altering autoimmune disease that can affect any organ of the body. Lupus is a disease which remains under-recognized and under-appreciated.

An autoimmune disease is one in which the immune system is unable to recognize the difference between healthy cells in the body and the foreign cells it fights to remove. A healthy immune system produces antibodies which attack and destroy foreign and invasive cells like viruses, bacteria and germs.

However, in people with lupus, the immune system creates auto antibodies which destroys healthy tissue. The

consequence of this can be widespread, causing damage, inflammation and pain throughout the body. Lupus is a potentially fatal disease. Most organs and other parts of the body can be affected, including the brain, heart, lungs, kidneys and skin.

This Event Is Observed Around The World

To raise awareness of lupus around the globe, during the early 21st century, a World Lupus Day was set for the 10th of May each year. This date was set following agreement by representatives of lupus organizations from 13 different nations worldwide.

Awareness events for World Lupus Day are held in most of the continents of the world including, North & South America, Europe, Africa, Asia and Australia. Lupus awareness day events can vary between nations.

Information originally posted on and © of whathealth.com

For more information, please see: <http://www.worldlupusday.org/index.html>

Download a flyer: www.worldlupusday.org/images/WLDFlyer.jpg

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FIRST
CLASS
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Antiphospho.....what?!?!

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.

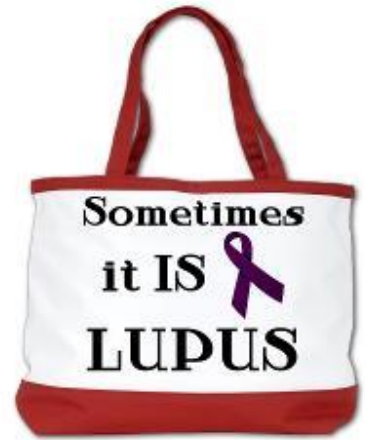
Sponsored by: **Kidd & Vogelpohl Family**



CafePress ~ APS & Lupus Awareness Items

We have a number of APS & Lupus Awareness items available. Some of them are shown here, but there are many more available! Our creative team is always working on new one of a kind designs and many more will be coming soon. CafePress is constantly adding new items and we try to update the store as quickly as possible to make those available to you. 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 percentage of each sale from our store when you buy from it, so not only will you get a quality item, but you will 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>