



ANTIPHOSPHO...WHAT?

APS Foundation of America, Inc. Newsletter

Volume 27

Spring/Summer 2013

Antiphospholipid Syndrome Alliance for Clinical Trials and International Networking (APS ACTION) Update #2

Written by: Emily Pflug (APS ACTION Volunteer) and JoAnn Vega, CCRC (APS ACTION Lead Coordinator)



Founded in 2010, APS ACTION is the first ever international research network that has been created to specifically design and conduct large-scale multicenter clinical trials in persistently antiphospholipid antibody (aPL)-positive patients. Please refer to volumes 24 and 26 of the APS Foundation of America's newsletter for more information.

APS ACTION has two major clinical research projects that are now open for recruitment. Interested patients can contact JoAnn Vega, CCRC (vegaj@hss.edu; 1-212-774-2291) or one of the centers below.

Project 1 - International Clinical Database and Repository ("Registry"): As of April 2013, 16 centers have received Institutional Board Approval (IRB) approvals (Table 1) to participate in the APS ACTION Registry.

The "Registry" is a secure, web-based clinical database and repository of persistently aPL-positive patients so that their natural course can be followed over 10 years. This project will allow us to study large groups of aPL-positive patients in a more organized way, facilitating a better assessment of clinical characteristics and problems, leading to improved management of aPL-positive patients.

The study consists of 11 study visits and 10 phone interviews, which will be conducted over a 10 year period. Each visit includes a standard physical examination and laboratory testing. If a patient develops new blood clots or pregnancy losses, they will be asked to complete an additional study visit.

To participate in the "Registry," patients must be between 18 and 75 years of age and have persistent (at least 12 weeks apart) aPL-positivity within 12 months prior to entry into the trial. aPL-positivity is defined as:

- Anticardiolipin Antibodies (aCL) IgG/M/A (> 40U, medium-to-high titer, and/or greater than the 99th percentile) and/or
- Anti- β_2 -Glycoprotein-I antibodies (a β_2 GPI) IgG/M/A (> 40U, medium-to-high titer, and/or greater than the 99th percentile) and/or
- Lupus Anticoagulant test positivity

Project 2 - A Multicenter International Perspective, Randomized Controlled Trial of Hydroxychloroquine (HCQ) for the Primary Thrombosis Prevention in Antiphospholipid Antibody Positive but Thrombosis-Free Patients without Other Systemic Autoimmune Diseases ("HCQ Study"): As of April 2013, seven centers have received Institutional Board Ap-

(Continued on page 5)

Follow APSFA



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!

Inside this issue:

APS ACTION Update #2	1
From the President / BOD	2
June Fundraiser	3
You Are Too Young	3
GO BURGUNDY!	4
Kidd-Vogelpohl 3rd Annual	5
Coumadin Failed Me	6
APS ACTION—Table 1	7
Donor Sheet	8
APS ACTION—Table 2	8
APS to CAPS	9
Are Alternative Treatments	10
Staying Sun Safe	11
May is Stroke Awareness Month	11
Lupus Awareness Month	12
Cafepress	14



Letter from the President



Summer is fast approaching me, with a 83°F plus degree temperature day with no sun. We seemed to have skipped Spring here, which is ok with me.

We have decided to go to bi-annual newsletters. No, you won't be missing out on information, the newsletter will just be larger. Due to my health and lack of articles to produce our usual quality newsletter, we decided to skip it to spare you a newsletter of filler. We read enough filler elsewhere. This newsletter does have some articles of interest to the APS population and to quality standard.

Café Press is growing again. We are adding more and more products every day. Check out our store at <http://www.cafepress.com/apsfoundation>. 100% of the profits from these products will go to the APS Foundation of America, Inc. We should have more designs coming soon as well.

Special thanks to Michael Selby for holding an Pamper Yourself Avon Fundraiser for the APSFA. We were able to raise \$325.00. Not to bad ladies and gents!

Remember to sign up for the e-Newsletter at <http://tinyurl.com/3rvb379>. As Facebook flops, my New Year's prediction, we will be relying solely on this e-Newsletter list, so please sign up. As we work more with APS ACTION more APS news will be coming out through research that was sponsored or co-sponsored by the APSFA.

We will be having a June APSFA fundraiser. For a donation of to the APSFA during June for \$35.00 or more you will be given a set of dragonfly earbuds. A \$10 value. They will be mailed out at the end of June. Limit one set of earbuds per household. Thank you for supporting the APSFA.

Despite my health, I have been able to catch up on a lot of things. (Now to get the house back in order.) Things are just being done quarterly now. My health has to come first.

That is about all the news I have to report. 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

PRESIDENT, CO-FOUNDER, EXECUTIVE DIRECTOR
Tina Pohlman, WI

VICE PRESIDENT, CO-FOUNDER, WEBMASTER
Heidi Ponagai, MI

SECRETARY
Dana Stuart, KS

CO-FOUNDER
Todd Ponagai, MI



MEDICAL ADVISORS

Thomas L. Ortel, MD, PhD

Director Duke Clinical Coagulation and Platelet Immunology Laboratories
Director Anticoagulation Management Service

Robert Roubey, MD

Division of Rheumatology & Immunology
University of North Carolina at Chapel Hill

Gale A. McCarty MD, FACP, FACR

President, RheumEd Consulting
Harborside, Maine

Keith R. McCrae, MD

Division of Rheumatology & Immunology
University of North Carolina at Chapel Hill

Al Lodwick, RPh, MA

Certified Anticoagulation Care Provider
Founder of the Warfarin Institute of America

Sheldon Paul Blau, MD

School of Medicine of the State University of New York at Stony Brook
Fellow of the American College of Physicians and a founding Fellow of the American College of Rheumatology

Adedayo A. Onitilo, MD, MSCR

Oncologist/Hematologist
Master of Clinical Science Research, Medical University of South Carolina
Assistant Director of Clinical Research-Eastern Division, Marshfield Clinic, Weston, WI

Audra Ford, MD

Family Medicine, Augusta, Georgia

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

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

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



June Fundraiser: Dragonfly Earbud Headphones

APS Awareness Month is quickly approaching and with it we are holding a special fundraiser that we think our readers will enjoy.

During the month of June anyone who makes a donation of \$35.00 or more to the APSFA will receive a pair of adorable dragonfly earbud headphones.

As you may know, the dragonfly is the official symbol we have chosen to represent Antiphospholipid Antibody Syndrome much like the butterfly symbolizes Lupus.

Donations must be made through the [donate button on our website using paypal](#) or else by check using the donation



coupon on page 8 of this newsletter. Donations must be received or post-marked by June 30 to qualify for the earbuds and please only one per household.

The headphones are very nice quality and feature adorable dragonflies on each ear bud as well as one on the cord. There are 3 different sized, flexible, acrylic inserts which makes them customizable for different sized ears. The earbuds also come with a zippered case with a key ring attached for convenient storage. The cord is 30 inches and the headphone jack is a standard 3.5 mm—so they are perfect for MP3 players and most smart phones!

You are too Young to Have This Much Wrong With You

Written by: Brandy Lee

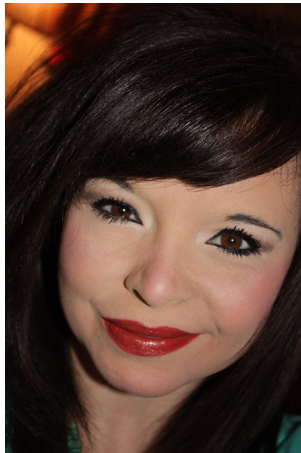
My name is Brandy Lee. I am 32 and was diagnosed with APS with SLE in 2008. I had symptoms that were undiagnosed for nearly ten years prior. I had a miscarriage, and the full term pregnancy I delivered, had many high risk complications. Including; appendix rupture, erythema nodseum, and stroke.

I was ill and hospitalized many, many times over a ten year period for fatigue, organ failures and everyone made me feel like I was crazy because they couldn't determine what was making me stay so sick.

I lost a job and a husband due to the many complications of my health. I have had numerous surgeries of organs that failed for no apparent reason such as my gallbladder, appendix and one physician nearly removed my spleen before they realized what was causing the enlargement.

In 2008 I had severe pain that lasted months and kept me from my busy career and motherhood. I sought a doctor who began running tests and found the APS with SLE with Raynaud's Phenomenon. I had a stroke in 2009 leaving my right side of the body paralyzed for nearly a year. With a great fight I have regained all but the use of the right side of the face.

I am on Coumadin Therapy and have began to not process the drug correctly, my INR goes from one extreme to another daily and as a result I threw a blood clot in a vessel in the ear canal and became deaf in the left ear as I slept. Hearing aids have helped restore some of the hearing loss.



I am currently working with my Rheumatologist to find a hematologist to explore alternative therapies such as Lovenox™ or heparin shots. We have been unsuccessful in maintaining a stable and suitable INR for months. I live in a relatively small town with limited medical expertise. I have found that the doctors are not familiar at all with this disease or how to treat it. I have had two doctors actually tell me they didn't know how to treat the disorders and handed me my medical file. It is extremely troublesome to have something that is not the common cold.

I walk into the doctors' office, a young attractive woman, and not only were they reluctant to run tests but some flat out told me you are too young to have this much wrong with you and they sent me on my way without having looked at one medical report.

When I finally found someone who would listen to me I broke down and cried for days. It was the greatest yet worst day of my life. For finally I was not crazy, I was ill with something that was real it had a name, it had a treatment, it had help! My life has not been the same due to the disease and many days I may curse it, and others I am thankful to have the time I would not have had otherwise to be with the miracle I did receive against all the odds which is my 8 year old daughter.

I have not been able to work since the stroke in 2009 and I concentrate on the good of each day and the joy of being around my child who was such a miracle to be born.

I am thankful for this organization and the resources it provides to people such as myself. Thank you!



GO BURGUNDY!!—Help the APSFA Spread Awareness!!

Written by: Heidi Ponagai

We are living in the age of the internet and one of the easiest and most effective ways of reaching hundreds of people is through social media sites and blogs. The APSFA has decided to step up our social media and blog presence to spread APS Awareness during the month of June to hopefully continue into the remainder of the year.

In order to be successful, we need APS patients our readers' help!

We are asking everyone to GO BURGUNDY with us in the month of June to spread APS Awareness.

If you are on Facebook, then you have probably noticed when multiple people change their profile picture or cover graphic in support of a certain cause or recent national news incident. The same type of thing happens on Twitter, Instagram, Pinterest, Tumblr, and on people's personal blogs as well.

In doing something as simple as changing a photo or posting a photo it helps to spread awareness for whatever the cause is. Think of how many people we can reach by just that simple gesture!!

How Can You Help?

What we're asking of you is to join us in posting photos of you or your family members—pets included—wearing burgundy, any of the APS Gear from our Cafepress store, or anything with dragonflies on it.

Do you have a burgundy dress? Wear it sometime in June, snap a photo of yourself and post it on Facebook.

Recently ordered an APS Awareness T-shirt from our Cafepress store? Take a selfie and post it on your Twitter feed.

Get a burgundy bandana for your dog or a ribbon for Felix the kitty. Snap a photo of them sitting pretty and post it to Instagram!

Or, the ever popular photos on Pinterest or Instagram are nails, as in fingernails. If you get yours done like I do, forgo the pink polish this June and pick a burgundy and let us see them!!

Same thing with dragonflies. Do you have them in your garden? Share with us! How about on your clothes? Show them off! Or jewelry? Let's see them sparkle!



We are also asking that people share posts. Share what other people post as far as APS Awareness goes. Retweet. Repin. Show us your burgundy!

Also, use hashtags. We will be using #GoBurgundy and #APSAwareness but anything that brings awareness to APS will work.

During the entire month of June we will be featuring photos that people post on the APSFA Instagram (like the photo above) and other social media pages. In order to do so we will need people to either tag us in them, put @apsfa or #apsfa in the comments of the photo, or use one of the two hashtags above.

There may also be some surprises in store for some lucky people who participate!!

One final thing. We are adding a new line of car magnets to our Cafepress store. We don't have burgundy ribbon shaped magnets, but we do have round, rectangle, and oval shaped ones. Some new designs are available as well as old favorites. Eventually we will be adding more but for now there will be a small, exclusive selection. And the nice thing about car magnets is that they stick to the metal and can be easily removed when you're ready for them to be.

We're trying to bring more awareness to APS in all the ways that we can and if you wait in any kind of traffic and are anything like I am then you read all the bumper stickers you see as the cars go by you. Spread APS Awareness on the go!

We hope that you will join us in turning the internet (through social media sites) BURGUNDY this June and throughout the year.

APSFA Social Media Sites:

Facebook: <https://www.facebook.com/APSFA>

Twitter: <https://twitter.com/APSFA>

Pinterest: <http://pinterest.com/apsfa/>

Instagram: <http://instagram.com/apsfa>

Blog: <http://apsfa.blogspot.com/>



(Continued from page 1)

proval (IRB) approvals (Table 2) to participate in this clinical trial.

Hydroxychloroquine (Plaquenil®) is a drug that has been used to treat malaria. It has an anti-inflammatory function and is currently approved by the Food and Drug Administration (FDA) for the treatment of systemic lupus erythematosus (SLE) patients. Hydroxychloroquine also inhibits platelet aggregation, which is a key step in blood clot formation.

The purpose of the “HCQ study” is to determine whether hydroxychloroquine is beneficial in reducing the blood clot formation in aPL-positive patients with no history of thrombosis. Over the course of the trial, 1000 patients will be randomized to receive HCQ or no treatment in addition to their standard regimen.

Participation involves 11 study visits and 10 phone interviews over a five year period. If a patient develops a new blood clot during the study period, they will be withdrawn from the trial and asked to complete a final visit.

To participate in the “HCQ Study,” patients must be between 18 and 60 years old and have persistent (at least 12 weeks apart) aPL-positivity within 12 months prior to the screening, which is defined as:

- Anticardiolipin Antibodies (aCL) IgG/M (> 40U, medium-to-high titer, and/or greater than the 99th percen-

tile) and/or

- Anti- β_2 -Glycoprotein-I antibodies (a β_2 GPI) IgG/M (> 40U, medium-to-high titer, and/or greater than the 99th percentile) and/or

- Lupus Anticoagulant test positivity

Patients may not participate in the trial if they meet any of the following exclusion criteria:

- History of Blood Clots (arterial, venous and/or biopsy proven small vessel)
- History of Transient Ischemic Attack
- Lupus Diagnosis
- Other Systemic Autoimmune Diseases Diagnosis
- Hydroxychloroquine or Another Antimalarial Drug within 3 Months
- Warfarin or Heparin within 3 Months
- Current Pregnancy

If you want to learn more about APS ACTION, please visit our website at www.apsaction.org or contact the APS ACTION Lead Coordinator, JoAnn Vega, CCRC, at (212) 774-2795 or at info@apsaction.org.

Tables 1 & 2 are on Pages 7 & 8

3rd Annual Kidd-Vogelpohl Bowling Fundraiser for the APSFA

Submitted by: JeriAnn Kidd



We can't believe it has been 3 years already since our beautiful Jessica passed from APS.

This year we were able to get a dear friend of mine, who is a news anchor, from Channel 5 in Cincinnati do an interview about APS and our fundraiser.

I have never done it in the past because it is so painful but I did give the okay this time. I just

want to yell from the hilltop that we need every hospital to be able to test for APS and know how to treat.

We lost 11 days at our local hospital who would have never been able to diagnose Jess because they don't test for it.

Within 24 hours of transferring her to UC we had a diagnose but they were even unsure how to treat.

I was so thankful to Dr. Ortel, with the APSFA's help, to get in touch with them and work together to make Jess better before her brain hemorrhage.

Edited by the APSFA to add: The Fundraiser was able to raise \$9,500.00 for the APSFA for Research and Medical Scholarships.



Coumadin Failed Me, But I Will Keep On Living!

Written by: Mary Sampson

I started getting sick when I was 20. I had no idea what was going on seeing as I had never been sick before this. I went from doctor to doctor and nobody could tell me what the deal was. I went thru so much testing including an MRI. We got a call from the doc that ordered the MRI and he told us to come to his office right away. We knew it wasn't going to be good. He said that my brain had tons of lesions and that it looked like I had MS.



We were devastated but we still had to get the conformation of the diagnosis from a neurologist. We went to see one and she said "You don't have MS." and walked out of the exam room. We were relieved to some extent but now we had to keep plugging along to see what I did have.

My health really started declining and I had to quit my job which meant that I lost my insurance. When I had no insurance... all of the testing and doctors appointments stopped. I ended up have to rely on the ER to be my really expensive and most of the time very unhelpful doctor because I had no other options. My husband had to rush me to the hospital one night and they found that I had severe pericarditis and fluid in my lungs. I was admitted and that when I was seen by a rheumatologist. He is still my doc. He was the only doctor that helped me and would do testing and appointments for little to no cost. He ended up sending me to get a full body CT scan. It showed that I had dead spots on both kidneys and spleen. He started me on Coumadin that day. I was on the Coumadin for 5

years and was never once therapeutic. I kept getting worse. The Coumadin was doing nothing and my ER and admissions were really adding up. I was put on Vioxx and methotrexate and countless other meds. I finally made the decision to start moving forward with my life in spite of what was going on. I started going to school for mortuary sciences and that about killed me (no pun intended) because I was sick and stressed.

Fast forward to 2008-- still no insurance, SSDI denied 3 applications saying that I wasn't "sick enough". I was still working towards my degree and then the worse happened...I suffered a stroke on November 17, 2008. I was 25. I was on 30mg of Coumadin a day (I weighed 129lbs) and my INR was at a 1.0. I had to get brain surgery done because the clot busting IV meds that they usually give didn't do anything on me. I spent a week in the ICU and another on the neuro floor. I lost the ability to speak and write. I started speech therapy the day after I got released from the hospital. It took 4 months to get most everything back. It was a hard process but I was very fortunate that it didn't take me out.

I am so lucky that I don't have any parilization. I do have mild dementia, panic/anxiety because it was a traumatic brain injury, horrible migraines and changes in life plans. I couldn't finish my degree because of my memory issues. Trying to work on cadavers and remember what bone is what during a practical exam when you have 30 seconds to answer was not going well. I went from an A average to D average. I had to drop out. The stroke bill was \$180,000.00 and that was just the hospitals bill. It didn't include all of the specialists and docs

that saw me when I had the stroke. I was lucky enough to have a hematologist take my case and cut me deals so we could try to figure this out. Tons of blood work later and we had a diagnosis...APS. He said that obviously Coumadin did not work with my system (I have all of the possible antibodies you can have...he said I was a strange case) and put me on lifelong lovenox...2 shots a day for the rest of my life. I was fine with stabbing myself so I didn't have another stroke!

I'm 29 now and still sick. I was able to get SSDI after hiring a lawyer...sad that it takes that when you are really sick. My husband that has been here thru everything is still here!! ;-) We are going on 10 years of marriage. We want to start a family. We took all of the proper steps and saw a fertility specialist who has dealt with APS pregnancies and he gave us the green light. We found out that we were pregnant but at my 11 week appointment, they did the third ultrasound and to our shock I was carrying twins but there were no heartbeats. We were crushed and I had to go into surgery the next day. I didn't have a choice in the matter. Lost so much blood during surgery that I was on the cusp of needing a blood transfusion. We were told to try again and we are. We want something beautiful to come out of this situation and I hope we can do it.

I have adopted the thought of "I'm sick. It's not going to stop me from living." I almost died with the stroke and with a few other complications from APS so there is a reason I'm still here. I just want to tell everyone that I'm sorry that we are all in this situation. It's not fair and doesn't make sense at all. But try to pull on whatever gives you comfort and strength whether it's God, family friends or a punching bag. ;-)



(Continued from page 5)

Table 1: APS ACTION Centers Participating in the International Clinical Database and Repository

Center Name	Investigator(s)	(*) Contact Person
Hospital for Special Surgery, New York, NY, USA	Doruk Erkan Jane Salmon Michael Lockshin	JoAnn Vega* vegaj@hss.edu (1) 212-774-2795
University of Brescia, Brescia, Italy	Cecilia Nalli Laura Andreoli Angela Tincani*	tincani@med.unibs.it reumatologia.immunologia@spedalicivili.brescia.it (39) 030 3995488/7
University of Texas Medical Branch, Galveston, TX, USA	Silvia Pierangeli*	sspieran@utmb.edu
University of Rio de Janeiro, Rio de Janeiro, Brazil	Guilherme de Jesus* Roger Levy	guilhermedejesus@gmail.com (55) 21 9959-4089
University of Athens Athens, Greece	Maria Tektonidou*	mtektionidou@gmail.com (0030) 2132061786
University of Milan Milan, Italy	Cecilia B. Chighizola* Pierluigi Meroni	cecilia.chighizola@unimi.it (39) 02 619112554
University Hospital Padova, Italy	Alessandra Banzato Vittorio Pengo*	vittorio.pengo@unipd.it (39) 04 98215658
University of São Paulo São Paulo, Brazil	Danieli Oliveira de Andrade*	danieli.andrade@hc.fm.usp.br (55) 11-30617176
University of Utah Salt Lake City, UT, USA	Ware D. Branch*	dwbranch@gmail.com (1) 801-581-8425
Hospital Universitario Cruces, Bizkaia, Spain	Guillermo Ruiz-Irastorza*	r.irastorza@euskaltel.net (34) 946006348
Peking University First Hospital Beijing, China	Zhuoli Zhang	Ji Lanlan, MD* thigh0829@163.com (0086) 13810485376
Hospital Clinic Barcelona, Catalonia, Spain	Guillermo Pons-Estel Richard Cervera*	rcervera@clinic.ub.es (34) 93 2275774
Hokkaido University Hospital Sapporo, Japan	Tatsuya Atsumi*	at3tat@med.hokudai.ac.jp (81) 11-706-5913
Johns Hopkins University Baltimore, MD, USA	Michelle Petri*	mpetri@jhmi.edu (1) 410-955-9114
Nancy University Nancy, France	Denis Wahl*	d.wahl@chu-nancy.fr (33) 383153869
CHU de Québec, pavillon CHUL Quebec, Canada	Paul R. Fortin	Davy Eng* Davy.Eng@crchuq.ulaval.ca (1) 418-525-4444 ext. 48280

(Continued on page 8)



Enclosed is my tax-deductible donation to the APS Foundation of America, Inc.

\$35 \$50 \$75 \$100 Other: _____

I am making this donation in honor or memory (please circle) of: _____

I would like this donation to be listed as Anonymous

Name: _____

Address: _____

City: _____ State: _____ Zip: _____

Country (If not USA): _____

Email Address: _____

Phone: _____

Please make checks payable and mail to:



APS Foundation of America, Inc.

Post Office Box 801
La Crosse, Wisconsin 54602-0801
Office: 608-782-2626 Fax: 608-782-6569

(Continued from page 7)

Table 2: APS ACTION Centers Participating in the Hydroxychloroquine Trial

Center Name	Investigator(s)	(*) Contact Person
Hospital for Special Surgery, New York, NY, USA	Doruk Erkan Jane Salmon Michael Lockshin	JoAnn Vega* vegaj@hss.edu (1) 212-774-2795
University of Brescia, Brescia, Italy	Cecilia Nalli Laura Andreoli Angela Tincani*	tincani@med.unibs.it reumatologia.immunologia@spedalicivili.brescia.it (39) 030 3995488/7
University of Texas Medical Branch, Galveston, TX, USA	Silvia Pierangeli*	sspieran@utmb.edu
University of Athens Athens, Greece	Maria Tektonidou*	mtektionidou@gmail.com (0030) 2132061786
University of Milan Milan, Italy	Cecilia B. Chighizola* Pierluigi Meroni	cecilia.chighizola@unimi.it (39) 02 619112554
University of Utah Salt Lake City, UT, USA	Ware D. Branch*	dwbranch@gmail.com (1) 801-581-8425
Peking University First Hospital Beijing, China	Zhuoli Zhang	Ji Lanlan, MD* thigh0829@163.com (0086) 13810485376



APS to CAPS: My Story

Written by: Richard Nix

I got my first clot around the age of 22, that was in 2001. No doctors could figure out why an otherwise healthy young man would be clotting without apparent reason. So, I was put on Coumadin™, and told it might be life-long.



Nine years go by, still no ideas on why I clot. I keep taking Coumadin™, and try to get my blood checked like I am supposed to. Then one day, something goes wrong. I am admitted to the E.R. with extreme pain in my hip.

Many tests are performed; X-Rays, MRIs, etc. It turns out that I am bleeding internally, but still clotting at the same time. Nobody has heard of this happening before. They give me large doses of Vitamin K to reduce my INR (international normalized ratio), how "thin" my blood is, in hopes of stopping the bleed. This is what should work for a normal person. I am about to find out that I am not normal. Morphine™ is administered every four hours through my I.V. but it doesn't really help, the pain was so bad. I begged my nurse to just give me enough to knock me out, "Please!", I begged. She didn't, but what she did do was start hiding, and not giving me my pain meds on time. She told my mother that I was a junky just looking for some meds.

I am not a junky, never have been. As a matter of fact, I avoid taking pain medication for anything. When I am given pain med. for something, I don't hardly use any, if at all. I don't want to be one of those people that needs horse tranquilizers to get rid of a little head-ache.

My mother called my wife, she was shuffling the kids between babysitters

so she could stay by my side, and told her what was said. So, my wife called my room and asked me how I was doing. I told her, "Something is wrong, Baby." She immediately called my Dr. at his office and told him what I said, he said "Oh Dear!" and dropped the

phone. He was just getting to work, it was early, so he cancelled his morning appointments and rushed over to check on me.

When Dr. Jeff arrived in my room, that nurse was nowhere to be found. He had to track her down. When she was brought into my room, he kind of patted my leg, and asked how I was doing, and what my pain level was right then. I told him it was about a 4 or 5. He then pointed out my blood pressure and heart rate to that nurse, then told her (I am not quoting, but this is how I heard it, sorry for the language) "This guy is in pain, his blood pressure is sky high and he says his pain is only a 4 or 5? I know him, he has been my patient for years, he is not a pill head. His pain tolerance is incredible, he's no p*ssy. Get him his pain medication, NOW!" After she returned, they had a little talk outside my room, with the head nurse on duty at the time, and he forbid her from being in my room, ever. I hope she got fired.

Since the morphine wasn't doing the trick, they decided to put me on Dilaudid™, that did the trick! I could sleep now.

After more tests, and consulting with other doctors from all over the country, or so I've been told, they figured out what was going on with me. The clotting, the bleeding, multiple organs af-

fectected. I had APS. Catastrophic APS to be more exact. I didn't know the diagnosis yet, because I had already fell into a coma.

I don't know how long I was out, but I remember waking up, sort of, with my bed tilted, feet up, while a doctor was doing something to my neck, it hurt. I asked him if I was supposed to feel it, he said it was ok, and he was almost done. He was putting a port in my neck for chemo and plasmapheresis. It turns out that this was the second time they had put one in, the first time it wouldn't work, so they put it on the other side instead. I passed back out.

I don't know how long it was, time is a blur from then. My wife told me that Dr. Jeff actually stayed by my side while I was in ICU all night, a couple of times. He had just gotten married, and he stayed with me overnight, that, my friends, is a good doctor!

I remember being in a lot of pain. I begged God to take me, let me die. I was ready, really. God spoke to me, told me that it was not time for me to go. I had to take care of my wife, my children. "Go to them" the voice said.

I woke up, and between my feet, taped to the footboard by my sister in law, was a picture recently taken, of my three youngest kids. I still get choked up telling this story. I started getting better, and was placed back into a normal room again. I have been in the hospital for over a month. A couple days later, I was put on a Medi-Flight to Rochester, Minnesota, the Mayo clinic.

I stayed there for about another month, slowly getting better. I lost a lot of strength, and weight. I didn't have spare weight to lose, I started out at about 200 lbs. when I went to the E.R.

(Continued on page 12)



Are Alternative Treatments for APS and/or Lupus Safe?

Written by: Christopher Repetsky, M.D. Candidate

More and more in today's world, we are hearing about "Alternative Medicine" and the promises of what it can do for our health. But, like so many complex topics, there exists a huge amount of information to wade through, not all of it being factual. It's very hard to tell who's right and who's wrong. However! The best way to sort out the fact from fiction is to look at the science behind the claims being made, and how they impact the truth.

First, we have to define what we mean by "Alternative Medicine". What exactly is it? Depending on who you talk to, it has very different definitions. This creates a problem, as it's difficult to find out exactly *what* you are discussing. For example, some people define diet and exercise as "alternative". This is a false claim, as physicians recommend and endorse both diet and exercise as meaningful tools for staying healthy. [1] Some say that herbal medicine falls under this category. Since herbs and extracts are currently receiving a lot of attention in the media, the internet, and other healthcare resources, the focus of this article will primarily be on them.

Herbs have been used for centuries to treat a wide variety of medical conditions, and with good reason. Many of today's modern pharmaceuticals are derived from things we find in nature, like our friend Aspirin which was derived from extracts of Willow Bark. The study of medicines derived from natural sources is called "Pharmacognosy". [2] These specialized scientists look for ways to make new medications based on compounds found in nature. Although Pharmacognosy is a legitimate field of study, we must not confuse it with the large amounts of unregulated supplements and extracts

being sold in the United States today. Many people think that if an herb or supplement is on the rack at their local store, that it must be effective and certified as safe. Sadly, this is not the case.

"As with many things in life, when it comes to herbals and supplements people rely more on the testimony of their friends and family than they do on solid research and science."

Due to a law passed in 1994 called the Dietary Supplement Health and Education act, supplement manufacturers themselves are responsible for the safety and efficacy of their products, not the government. [3] This creates a double standard in which medications that your physician prescribes you (from a pharmaceutical company) have to be tested and shown to work, as well as be safe. Supplements and herbals do not. This is worrying to many physicians, as many of these supplements are able to interact with drugs you are already taking, or even have detrimental effects on the body. With no good research showing that they work or are safe, how are we to know how to manage them?

As with many things in life, when it comes to herbals and supplements people rely more on the testimony of their friends and family than they do on solid research and science. For example, someone might tell you "Hey, I took this herb and I never got headaches anymore!" In the realm of science, this is called an "anecdote". Anecdotes are stories we tell each other about things we have experienced, but don't necessarily have evidence to back them up. Because of this, anecdotes are not considered good evidence of anything, as we have no way of confirming what actually happened. In our little story above, taking an herb may have indeed caused a reduction in headaches. But do we know that for sure? What if coincidentally, the person also started exercising, or

changed their diet? What if they also started taking Ibuprofen at the same time as the herb? These are simple variables, but they show that many things can happen to confuse our view of how things actually occurred. Most important of all, the placebo effect can occur. This means you are feeling a certain way or showing certain results, but really nothing is happening. All people are susceptible to the placebo effect, even scientists! That's why when testing new medications, we have a placebo group during the trial to compare the real drug to. If the drug only works as good as placebo, we know that drug probably isn't very effective and we move on to something else.

As mentioned previously, herbals and supplements can be dangerous. Just because they are not a pill doesn't mean they are not able to act as one. Many popular ones interact with medications your doctor may have you taking, which can either lessen their effect or make them too powerful. This can make you very sick. For example, let's take Warfarin (Coumadin), an anticoagulant used by many patients with APS. It reacts with a surprising number of herbal medications, some of which can be life threatening. [4] This list includes: Ginger, Garlic, Ginseng, Ginkgo biloba, borage (Starflower) oil, some fish oils, St. John's Wort, and Cranberry Juice. If a patient is taking Warfarin along with any of these, this could alter the results of blood tests that you receive at the doctor's office, potentially making your doctor think something is either wrong with you when it isn't, or that you are at baseline when you aren't. For these reasons alone, it's important to ALWAYS tell your doctor when you are taking anything medically, even things you consider "Alternative".

(Continued on page 13)



Staying Sun Smart: Common Sense Advice for an Active Outdoor Summer

Written by: Heather Rogers, MD

As the grey winter months fade away and warmer weather beckons you outside, the first thing you'll want to do is dump those layers and feel the warmth of the sun's rays on your skin. Why not—it's that time of year.



you'll like and use regularly with SPF rating of at least 30 to provide full UVB and UVA protection. Remember to apply it to any area of your body that is exposed to the sun, and just as importantly, plan to reapply it frequently. Sunscreen becomes less effective the longer you leave it on, so a good rule of thumb is to reapply every two hours.

protection — The American Academy of Dermatology also recommends seeking shade when the sun's rays are the strongest, from late morning to mid-afternoon. Another source of UV rays that sometimes gets overlooked is reflection from water, snow and sand, so don't assume that you only need to watch out for sunlight from above.

Overexposure to the sun can lead to cosmetic concerns like wrinkles, age spots and broken blood vessels. Other effects can be more damaging and significant, including cancer. The number of women under 40 diagnosed with basal cell cancer has more than doubled in the last 30 years. Protecting ourselves from these effects starts with smart decisions to safeguard our skin.

Heather Rogers, MD, is a board certified dermatologist who specializes in the prevention and treatment of sun damage and skin cancer. She is an active member of many medical societies including the American Academy of Dermatology.



Clothing

Covering up in another essential part of effectively protecting your skin. We've come a long way from the first shirts with UPF rating (the term used for sun-protective apparel) that resembled burlap sacks. Quality rash guards and sun shirts that work great in and out of the water are now available in a variety of styles for children or adults. Wear a hat and sunglasses to provide protection for your face, eyes, ears and head.

Location

If your plan is simply to slather on sunscreen, soak up hours of rays and think you're protecting yourself, think again. Sunscreen is only one part of the sun

The season's longer days and milder temperatures can be the perfect time to revel in your favorite outdoor activities. But unless you are sun smart, even the mild spring sun can damage your skin, leading to age spots, wrinkles and yes, skin cancer. No matter the time of year, it's important to recognize that the rules don't change when it comes to protecting your skin against the sun's damaging rays. Here's a primer on how to smartly indulge your spring fever.

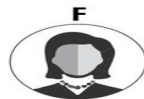
Sunscreen

Find a broad-spectrum sunscreen

May is National Stroke Awareness Month.

Approximately 795,000 strokes occur in the US each year. Recognizing the symptoms and acting quickly can help save lives and limit permanent disabilities. The National Stroke Association recommends the FAST technique for identifying potential signs of a stroke:

Spot a Stroke F.A.S.T.



FACE
Does one side of their face droop or feel numb? Ask them to smile.



ARMS
Does one arm feel weak or numb? Ask them to raise their arms.



SPEECH
Are they having difficulty speaking, or is their speech slurred? Ask them to repeat a simple sentence.



TIME
Even if these symptoms seem to improve, call 9-1-1 immediately.

Stroke is the fourth leading cause of death in America and a leading cause of adult disability*.

There is strength in numbers! Help spread the word!

Each time this infographic is "Shared", the PLAC Test will donate \$1* to the National Stroke Association.

For more information on Stroke, including common risk factors, please visit placetest.com/stroke



Brought to you by: PLAC Test for Lp-PLA2

* National Center for Chronic Disease Prevention and Health Promotion, Division for Heart Disease and Stroke Prevention.

FMD-14-011 Rev. 01



(Continued from page 9)

and when I left Mayo clinic, I weighed about 145. I am 6'3", that is thin.

I went home at the end of May, 2010. My wife and I rented a car, she drove, a couple days after my release. Time to go home.

After getting home, I was still in rough shape, I couldn't walk unassisted, so my father in law gave me a cane. I was so tired, and would get winded just getting a drink from the kitchen. My wife thought it was just depression at first, until she got a good look at me when I had tried to get a drink. I had asked her for one, but she told me I had to get up, I couldn't lay around and give up. Well, when she saw me do that, and my lips turned blue, she figured out I wasn't being lazy. She called Dr. Jeff right then, and I was squeezed in an hour later. When he saw me, he sent me straight back to the hospital. Great.

Well, after some more tests and monitoring, it was deduced that my adrenal glands had failed. Nice.

I got better, slowly. I went back to work, I am bull-headed like that, against everyone's advice. I had to take care of my family! Bad decision. I wind up getting sick a lot, going back to the hospital like 15 more times over the next year, until, finally, I get fired. Now I am trying for disability.

That's where I am right now. Waiting.

I have basically known since I was 22 years old how I was going to die. I will be 33 in February. I know I shouldn't be alive right now, hell, most don't live through what I survived. But I did, I am alive. So I think God for the gift He gave me, one more day.

I have APS, APS does not have me.

May is Lupus Awareness Month – a time for everyone to come together to raise awareness of lupus, an unpredictable and sometimes fatal disease, and show support for the estimated 1.5 million Americans and at least five million people worldwide affected by the disease. As part of Lupus Awareness Month activities, **World Lupus Day** is observed on May 10 – a day when the global lupus community rallies to bring greater attention to this terrible disease.

Lupus is more widespread than most people realize. In fact, research shows most Americans know little or nothing about lupus and its devastating impact. We can change that, but we need your support!

Band Together. Tell the Story. Change Lives. The Lupus Foundation of America offers many ways the public can join the Lupus Foundation of America and **Band Together for Lupus Awareness** during May. Lupus Awareness Month activities include social media, online, and grassroots components to empower individuals, organizations, and companies with a wide-ranging number of tools and resources to educate their communities about lupus. Visit www.lupus.org/awareness to learn more.

The History of Lupus Awareness Month

- As part of its founding principles, the Lupus Foundation of America spearheaded the national effort to bring greater attention and resources to lupus.
- The first lupus awareness observance occurred in 1977 when President Carter signed Public Law 95-72 which declared September 18-24, 1977 as National Lupus Awareness Week. The week long observance was moved to October in 1982.
- The first month-long observance occurred in 1986 when President Reagan signed Public Law 99-365 designating October 1986 as Lupus Awareness Month. Subsequent congressional designations occurred in 1987 and 1988.
- There was not any official congressional action designating October as Lupus Awareness Month after 1988. The October observance became a tradition throughout the lupus community for many years.
- In 2004, the first World Lupus Day observance was conducted in New York City in conjunction with the Seventh International Congress on SLE and Related Conditions. More than 100 lupus organizations worldwide observe World Lupus Day on May 10, generating increased visibility for lupus around the globe.
- In 2009, the Lupus Foundation of America moved the annual Lupus Awareness Month observance to May. May provides many opportunities, including Mother's Day, National Women's Health Week, and Women's Health Check-up Day to promote awareness of lupus, and show support for those who suffer from the disease. The warm weather is a good time for outdoor events and represents an opportunity to take charge of your health. The World Lupus Day observance also serves as the marquee event for a month-long series of activities designed to educate the public about lupus symptoms and its devastating impact.

Band Together. Tell the Story. Change Lives. Today, Lupus Awareness Month serves as a centerpiece of the lupus community's annual grassroots effort to raise awareness of this unpredictable and sometimes fatal disease, secure funds for lupus research, and support those who suffer from the disease. We need everyone's support to fight lupus and find a cure!



(Continued from page 10)

Most people don't want to hear it, but there really are no good "natural" replacements for many of the drugs people are prescribed. This isn't due to pharmaceutical companies being greedy or unethical, it's merely because we have yet to find via solid research anything that works that well. Rest assured, if a pharmaceutical company could find an easy way to treat a condition with a simple plant, they would certainly incorporate it into their products for easy money. Most of the popular supplements you hear about today have been thoroughly researched in the past, and the reason we aren't using them in "mainstream" medicine is simply because they aren't effective, not safe, or we have a medication that does the job better or with fewer side effects. Of course this can be frustrating for many, but like any topic, it's worth discussing with your doctor.

Many people also believe in the "money gambit". They prefer using herbals and supplements because they think medications are just a ploy by "Big Pharma" to make money or keep people sick. However, one must remember that supplement companies make millions of dollars themselves on their products. If the pharmaceutical companies are guilty of it, so too are the supplement manufacturers.

Remember that while there are many ways to manage illness, the absolute safest and most effective thing you can do is use methods with solid research backing them. This ensures that you are getting the best possible chance to affect your health positively, and remain healthy. If you are currently using herbals or supplements to treat a condition, a good plan would be to speak with your physician to verify that your treatment is indeed work-

ing, and is safe. However, not all physicians know or are qualified to comment or manage herbal medications. This is why it is always important to do your own research from reputable sources to confirm that your doctor's information matches what is actual fact. Physicians are human too, and are susceptible to the same marketing hype as we all are. To get you started, here are some excellent resources I have found to be particularly reliable:

www.quackwatch.com

(Maintained by Dr. Stephen Barrett, QuackWatch started out as the National Council Against Health Fraud and now exists as a non-profit consumer advocate designed for researching alternative treatments and claims. It is one of the biggest, most comprehensive sources about Quackery on the internet. QuackWatch is funded purely by private donations, and receives no funding from Pharmaceutical, Corporate or Lobbyist groups.)

www.sciencebasedmedicine.org (The SBM Blog is managed by Dr. Steven Novella, and includes many talented team members such as Dr. Harriet Hall, Dr. David Gorski, and Dr. Mark Crislip. Every weekday, a post is authored by one of the team members focusing on an important topic in Science Based Medicine, most of which revolve around alternative medicine. Like QuackWatch, the SBM site is not funded by any groups that could be considered a conflict of interest (IE: Pharmaceutical companies, etc.))

naturaldatabase.therapeuticresearch.com (The Natural Medicines Comprehensive Database houses and reviews a staggering list of research on natural medications. It requires a subscription, but is well worth it for those interested in unbiased information about such topics.)

Lastly, one concerning practice that has been cropping up lately is the practice of physicians selling herbs and supplements in their office. In today's world of

slick marketing and advertising, it's easier than ever to make a quick buck and some physicians sadly resort to doing this. The truth is, there is NO legitimate medication that a physician can prescribe you that you cannot obtain from a pharmacy. If your physician is selling products directly from their office, it is for their own profit. Don't fall prey to this marketing tactic. Sadder still, some unscrupulous physicians will recommend you products simply *because* they do sell them in-house, not because you necessarily need them for good health. Again, don't fall victim to this tactic.

So what's the bottom line? There's a lot of trickery and false claims out there. For something as important as your health, be sure to be well educated. Utilize scientifically sound sources for your research, not thinly veiled marketing sites (especially those that have a product to sell). Always think twice about blindly trusting the anecdotes of a friend, family member, or stranger. And always make sure you are on the same page as your physician concerning your current health.

1. "Healthy Eating." *Healthy Eating*. American Medical Association, <<http://www.ama-assn.org/ama/pub/physician-resources/public-health/promoting-healthy-lifestyles/healthy-eating-resources.page>>.

2. "About the ASP - The American Society of Pharmacognosy." *The American Society of Pharmacognosy*. The American Society of Pharmacognosy, <<http://www.pharmacognosy.us/what-is-pharmacognosy/>>.

3. "Dietary Supplements." U.S. Food and Drug Administration, <<http://www.fda.gov/Food/DietarySupplements/default.htm>>.

4. Lininger, Schuyler W. *Drug Interactions with Vitamins and Herbs*. Rocklin, CA: Prima Health, 1999. Print.



APS Foundation of America, Inc.
Post Office Box 801
La Crosse, WI 54602-0801

Phone: 608-782-2626
Fax: 608-782-6569
E-mail: apsfa@apsfa.org
Website: www.apsfa.org
Online Support: www.apsforum.com

FIRST
CLASS
STAMP



Antiphospho.....what?!?
Our Mission Statement

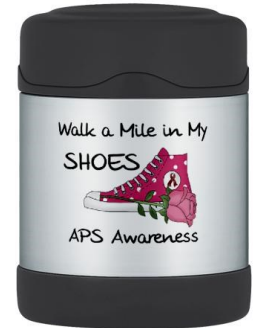
Founded in June 2005, the APS Foundation of America, Inc. is dedicated to fostering and facilitating joint efforts in the areas of education, support, research, patient services and public awareness of Antiphospholipid Antibody Syndrome in an effective and ethical manner.

Sponsored by: **Kidd & Vogelpohl Family**



CafePress ~ APS & Lupus Awareness Items

If you haven't seen our CafePress store lately, now is a great time to do so, especially since APS Awareness Month is here! Our creative team will be working overtime on brand 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!! Plus, wearing or using APS Awareness gear is a super easy way to spread awareness! Check out our store at the address below and be sure to check back often.



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

