



ANTIPHOSPHO...WHAT?

APS Foundation of America, Inc. Newsletter

Volume 24

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

Written by: Joann Vega, CCRC (APS ACTION Lead Coordinator), Aaron Greenberg (APS ACTION Volunteer), and Doruk Erkan, MD, (APS ACTION Executive Committee Chair)

Introduction: AntiPhospholipid Syndrome Alliance For Clinical Trials and International Networking (APS ACTION) is the first-ever international research network that has been created specifically to design and conduct well-designed, large-scale, multi-center clinical trials in persistently antiphospholipid antibody (aPL)-positive patients. The network is composed of a multidisciplinary group of physicians and investigators from around the world interested in APS research.

The founding principal of the APS ACTION is that it is an internationally collaborative effort, open to qualified investigators across the globe who are committed to further our understanding of APS and its management. APS ACTION currently consists of 31 members from 20 international centers. The number of APS ACTION members/centers is expected to increase in the near future as new membership applications are being accepted since November 2011.

Background: Antiphospholipid Syndrome is an autoimmune disorder in which autoantibodies, namely antiphospholipid antibodies, may lead to blood clotting and pregnancy losses. While APS has been well-recognized over the last two decades, there still remains a lot of ambiguity about: a) how aPL result in clinical problems; b) the clinical significance of current diagnostic aPL tests; and c) the optimal management aPL-positive patients, with or without history of blood clots.

The International Congress on aPL is held every three years to discuss the recent advances and future directions in APS. The "13th International Congress on aPL", chaired by Dr Silvia Pierangeli, was hosted in Galveston, TX, USA on April 13-16, 2010. The APS Clinical Research Task Force was a

committee formed by the "13th International Congress on aPL". The primary goal of the APS task force was to evaluate the global limitations of APS clinical research and develop guidelines for researchers to help improve the quality and quantity of APS clinical research studies.

APS | ACTION
ANTIPHOSPHOLIPID SYNDROME
ALLIANCE FOR CLINICAL TRIALS
& INTERNATIONAL NETWORKING

Following a systematic working algorithm, the Task Force identified five major limitations of APS clinical research: (1) aPL

detection has been based on partially or non-standardized tests, and clinical APS research studies have included patients with varied aPL test profiles with different clinical event risks; (2) clinical APS research studies have included a varied group of patients with different aPL-related manifestations (some controversial); (3) assessment of other blood clot risk factors are not always incorporated in APS clinical research; (4) most APS clinical studies include patients with clinically not significant aPL test results; furthermore, study designs are mostly retrospective (studies that look backwards) with limited number of prospective (studies looking forward) and/or controlled population studies; and (5) a lack of the understanding the particular mechanism (how it occurs on a molecular level) of aPL-mediated clinical events limits the optimal clinical study design.

As a conclusion, the APS Clinical Research Task Force saw that there was an urgent need for an international multi-center collaborative effort to design large scale clinical trials of persistently aPL-positive patients. Thus, an international collaborative working Summit was held in Miami in November 2010 that resulted in the formation of an international research alliance entitled: AntiPhospholipid Syndrome Alliance For Clinical Trials and

(Continued on page 9)

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SHARE

Patient Stories & Articles Needed!

We are in **need** of patient stories to feature in our newsletters. Every APS patient has a story to tell and yours could be shared with the entire APS community.

We also need related articles such as book reviews, poems, recipes, interest articles, quotes, etc.

If you are interested in sending us your story, please write to articles@apsfa.org and we will send you our guidelines.

Without your help our newsletter cannot be a success!

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Letter from the President

Wow, March in Wisconsin and then flowers are coming up from the ground, our apple orchards are in bloom, and 82°F outside. We really didn't have much of a Winter and I am not complaining.



We are in need of patient stories to feature in our newsletters. Every APS patient has a story to tell and yours could be shared with the entire APS community. We also need related articles such as book reviews, poems, recipes, interest articles, quotes, etc. If you are interested in sending us your story, please write to articles@apsfa.org and we will send you our guidelines. Without your help our newsletter cannot be a success!

We are also please to announce there has been a greater demand for our services and information packets. We are in need of donations to get items printed and postage paid for as we realize many of our clients are unemployed, low income or disabled and can not afford to make a donation to get this information to them. With our generous donors' help, we have been able to provide these services & information free of charge and hope to continue to do so.

Café Press is growing again. We are adding more and more products everyday. 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.

Remember to sign up for the e-Newsletter 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.

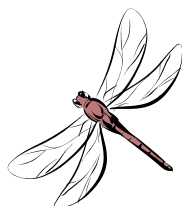
I must apologize that I am still behind on some APSFA items. Between my health, my numerous doctor appointments, lab draws, chronic pain and other responsibilities in my personal life I have just been swamped. I am trying to find a whole day where I can sit down and devote time to get it all done at once. Finding a whole day lately has been the problem. So, please bear with me.

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



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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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Travelers Thrombosis

Written by: B. Bartle, Pharm.D.

Travelers' thrombosis refers to the development of a deep vein thrombosis (DVT) or a pulmonary embolus (PE) after long distance travel. The association between travel and these types of blood clots has been known since the 1950's, but recent research and the publication of rare fatal cases by the lay press have made this condition a common concern among travelers. We can now give more appropriate advice than we could a few years ago.

Travelers' thrombosis can occur as a result of long distance travel by plane, bus, train or car. This condition was initially thought to occur only after long airplane flights, and was called "economy-class syndrome" by some medical authorities, wrongly associating it only with the cramped space of a regular airline seat. The common 'thread' for all these scenarios is prolonged immobility in the sitting position, which can produce significant blockage of blood flow from the lower legs. It appears that the longer the trip the greater the risk. Air travel may be associated with additional risk factors, such as the pressurized and dry air within the cabin, and dehydration due to excessive alcohol consumption. Symptoms of the DVT/PE do not usually develop during the flight or immediately after the flight, but tend to appear anytime from 3 days to 2 weeks after the trip.

PE arise in about 1 to 4 persons per million passengers. A DVT probably occurs a little more frequently. Small clots in the veins below the knees that rarely lead to symptoms or require medical attention may occur in as many as 1 in 20 travelers.

This information tells us that for the average healthy traveler the risk of a serious blood clot that requires urgent medical attention is extremely rare. Any of the following factors, however, may increase the risk of an individual long-distance traveler developing venous thrombosis:

- Being elderly
- Previous blood clots (but not presently on therapy to prevent them)

- A documented inherited clotting abnormality
- Pregnancy or the first few weeks after delivery
- Active Cancer
- Severe heart failure or recent heart attack
- Recent surgery, especially involving the legs
- Estrogen therapy (birth control pills or hormone replacement therapy)
- Obesity

Patients already receiving an oral anticoagulant such as warfarin, and having a therapeutic INR before travelling, are likely protected from any risk of developing travelers' thrombosis.

PREVENTION

A number of general measures can be taken to minimize the risk of travelers' thrombosis. A group of internationally-recognized thrombosis experts have suggested the following steps for persons taking trips of greater than 6 hours:

- avoidance of constrictive clothing around the lower extremities and waist
- keep well hydrated with non-alcoholic beverages
- frequent calf muscle stretching

Most travelers, including those with some of the risk factors listed above, do NOT require any additional preventive measures. For a small proportion of long-distance travelers with additional risk factors as listed above, in addition to the general strategies mentioned, consideration may be given to using properly fitted, below-knee graduated compression stockings, or a single injection of an anticoagulant belonging to the class of low molecular weight heparin. To maximize the effectiveness of

the injections, the patient should be taught to self-inject, if possible, immediately before boarding the plane, if that is the method of travel. Any of the above mentioned class of drugs, prescribed as a pre-filled syringe of the standard prophylactic dose for that drug would be appropriate. You or your nurse should teach the patient how to inject.

Aspirin and other anti-platelet drugs do not appear to protect against blood clots associated with long-distance travel.

People travelling by land should take advantage of the planned stops by buses or trains or stop their car periodically to take short stretches of walking.

Patients taking warfarin should have an INR blood test done within a week of a planned long-distance trip.

In summary:

The risk of developing a blood clot related to long-distance travel is very low. For most people, just following the general measures mentioned above is adequate. If you have special concerns about a particular patient that might have an additional risk of developing a blood clot associated with an upcoming trip, consider suggesting that the patient get a below-knee graduated pressure stocking or prescribe an injectable anticoagulant for both departures.

References:

Brenner B. Interventions to prevent venous thrombosis after air travel. Are they necessary? Yes. J.Thrombosis Haemostasis 2006;4:2302-5

Rosendaal FR. Interventions to prevent thrombosis after air travel: are they necessary? No. J. Thrombosis Haemostasis 2006;4:2306-7

Reviewed by: B.Geerts MD, M-F. Scully MD

Resource: [The Thrombosis Interest Group of Canada](#) consists of a group of 50 Canadian health professionals in fields related to thrombosis who collaborate to write evidence-based or consensus-based clinical guides on the investigation, management, and diagnosis of thrombotic disorders.



Alcohol Interactions with Coumadin®

Written by: Al Lodwick, RPh, MA (retired)

Alcohol interacts with warfarin (Coumadin®, Jantoven®) to either raise or lower the INR depending upon how it is used.

The best advice is to not drink alcohol while you are taking warfarin (Coumadin®, Jantoven®). Since this is not practical for everyone, this discussion will let you know what your risks are. The easiest warfarin (Coumadin®, Jantoven®) patients to manage are those whose lives follow routines.

Intermittent, occasional or binge drinking tends to raise the INR. This means that your body is acting as if you are taking more warfarin (Coumadin®, Jantoven®) than you really are. This increases your risk of having a rectal bleeding episode. Saving up all of the drinks you would have had for the week and having them all at a special occasion is one of the worst things you can do. A study of the use of alcohol in medications offers some insight as to how this works. The most common protein in the blood is albumin. Most of the warfarin that a person takes in a dose physically binds to albumin. The warfarin that is bound is then inactive. Alcohol appears to lower the amount of warfarin that is bound to albumin. The unbound warfarin is the part that has an effect on the clotting factors. Therefore, the INR will increase because there is more warfarin working in the body.



Daily moderate alcohol use (1 or 2 drinks - no more) has little effect on the INR. Whether or not it raises the risk of gastrointestinal bleeding is an unanswered question. Some people's attitude is, "If I cannot have a glass of wine with dinner, then I

won't take warfarin." Taking warfarin (Coumadin®, Jantoven®) in this case is probably better for you than not taking it. However, the important word is "probably". Whether or not this is true is not proven.

Daily alcohol use of greater than three or more drinks will result in the possibility of several things happening. First, the enzymes that metabolize the warfarin (Coumadin®, Jantoven®) can become more active. This means that the INR test will show that you are not taking enough warfarin (Coumadin®, Jantoven®). Then your warfarin (Coumadin®, Jantoven®) dose will be increased. Should you suddenly stop drinking, the INR will shoot upward and increase your risk of bleeding. The other thing that might happen is that the alcohol will irritate the lining of your gastrointestinal tract. If this gets some bleeding started, it can be very difficult to stop.

Reference: Tatsumi A. et al. Effect of ethanol on the binding of warfarin enantiomers to human serum albumin. *Biol Pharm Bull* 2007; 30: 826-9.

Ibuprofen & Interactions with Coumadin®

Written by: Al Lodwick, RPh, MA

Brand Names: Motrin, Advil, Motrin IB, Genpril, Haltran, Maximum Strength Midol, Menadol, Nuprin, Pedia-Care Fever, Vicoprofen, and many others.

Ibuprofen can cause gastrointestinal bleeding. If this should occur and you are taking warfarin, a minor bleed could turn out to be a major bleed.

There are three factors that contribute to this:

- Physicians are careless in their prescribing of ibuprofen.
- Patients are careless when they purchase ibuprofen as a non-prescription item.
- There is no warning that this is about to happen because the INR is not raised.

If at all possible, ibuprofen use should be avoided when you are taking warfarin.





Faces of APS ~ The APSFA Needs Your Help!

Written by: Heidi Ponagai

The APS Foundation of America, Inc (APSFA) is collecting photos for the Faces of APS Slideshow. Photos may also be used to post on our website, future newsletters, or advertisements if a patient story is included. All pictures must be submitted to the APSFA electronically in accord to the specifications outlined here: <http://www.apsfa.org/docs/Faces%20of%20APS.pdf> previously.

Many APS patients find it comforting to read other patients' stories and find out that they are not alone in their disease. We always include at least 2 patient stories in our quarterly newsletters.

We strive to bring you the best newsletter that we can each quarter. In order to do so, we need patient stories and stories of interest from APS patients and their loved ones.

Topics can be from how APS affects you, poems you have written, tip and tricks that help you get through your day, to your favorite recipe. We are also taking book reviews of publications listed on our suggested reading page at: <http://www.apsfa.org/publications.htm>

Please follow our current guidelines when submitting an article:

- Send your story/article to articles@apsfa.org
- Patient stories and most articles should be approximately 500-750 words long
- Articles should be written at a 5th-8th grade reading level
- Please try to include a picture when submitting a patient story
- Patient stories should read like an autobiography—generally from diagnosis to present time, but it doesn't have to
- Please also include a title of your story

Please use previous patient stories as your guideline. They can be found here: <http://www.apsfa.org/newsletters.html>

If you have ideas not listed here and are not sure if it would be appropriate? Drop us an email at articles@apsfa.org.

My Foot Almost Killed Me

Written by: Tina Turner

First my foot got really sore. I looked on the internet and decided it was gout. My foot turned white and was very cold and ached. I lived on painkillers but didn't see a doctor, just limped around. On a holiday to Bali, I had a foot massage and it relieved the pain, what it had done was dislodge the blood clot and from that moment, I was a ticking time bomb waiting to explode.

I was sitting with my brother and another friend having a drink on a Friday night. At 36 years old, a single parent to an active eight year old son and enjoying a busy full time job as a pharmaceutical sales representative. I was very rarely ill. Suddenly it felt as if I was free falling, yet I was still seated in my chair. I couldn't speak to tell the others what was happening, I didn't know what actually was occurring but it was terrifying, I thought I was going to die. I remember listening to them continuing to talk as they did not notice anything wrong with me. When the falling feeling stopped, I got up and told them I was going to bed. In the morning I felt better but started having severe sudden dizzy episodes. What I did not know was that I had suffered from a stroke. When I finally saw a doctor my blood pressure was 300/155. My doctor sent me immediately for tests which showed the stroke. My renal doctor diagnosed APS after 3 months. He rang me at home one night to tell me that he had tested my blood and that I had primary APS. For somebody my age and health to have suffered a stroke and have such high

blood pressure for no reason had left him puzzled and he was pleased that he had found the cause – so was I !!

I developed epilepsy as a result of the stroke and find that whenever my INR is outside of range I get terrible vertigo which doctors here in New Zealand think are small blood clots in my vestibular system or a small stroke. It has taken me almost 4 years to be able to work again but I have just started back this year and it is going really well. I take 13 mg warfarin per day. Nobody that meets me knows that I have any type of illness or have had a stroke because it has not affected me on the outside in any way.



On the inside it has made me so much more considerate of those less fortunate, it has helped me value my life so much more, made me so thankful to all my family and friends for all their help and support and of course so grateful to have the time to enjoy my life and never to take it for granted. Each night when I swallow my pills I get to remember the joy it is to be here and each night I never forget to take the time to think about what I am grateful for. I never did that before I had APS and for that I am truly grateful ☺



About Deep Vein Thrombosis (DVT)

By: Todd Ponagai

Deep-vein thrombosis (DVT) is a common but serious medical condition that occurs in approximately 2 million Americans each year.¹ DVT occurs when a thrombus (blood clot) forms in one of the large veins, usually in the lower limbs, leading to either partially or completely blocked circulation. The condition may result in health complications, such as a pulmonary embolism (PE) and even death if not diagnosed and treated effectively.

Learn the risk factors, signs and symptoms for DVT

The symptoms of DVT may be subtle and difficult to detect. When DVT is spotted early and properly treated, the risk of complications is reduced. When left untreated, it may cause severe complications, some even fatal. Pulmonary Embolism, a complication from DVT, kills up to 300,000 people a year in the U.S. — that's more than AIDS and breast cancer combined!¹

Learn what DVT is, the risk factors, the symptoms, and the preventative measures you can take to reduce the risk of DVT blood clots.

The best way to reduce your risk of DVT is to talk to your doctor about your risks, especially if you have cancer or certain heart or respiratory diseases.

Get the facts



Download "[DVT at a Glance](#)"

About the Coalition to Prevent Deep-Vein Thrombosis: In February 2003, more than 70 organizations assembled at the Public Health Leadership Conference on Deep-Vein Thrombosis (DVT) in Washington, D.C. to discuss the urgent need to make DVT a major U.S. public health priority. As a result of this meeting, which was co-hosted by the American Public Health Association (APHA) and Centers for Disease Control and Prevention (CDC) and funded by sanofi-aventis, participants agreed to establish a Coalition of organizations committed to educating the public and healthcare community about DVT.

In August 2003, national thought leaders and representatives from key organizations, including the American College of Chest Physicians, the APHA and the Society of Hospital Medicine met to set and guide the direction of the Coalition to Prevent DVT. A key outcome of this meeting was the decision to sponsor DVT Awareness Month, a campaign to bring DVT into the public eye on a national and local level.

Resource:

Coalition to Prevent Deep-Vein Thrombosis at <http://www.preventdvt.org/>. Last accessed on March 17, 2012

Last Time / This Time

Written by: beecute

Last Time

I blamed Bayer Shering Pharma
For the Clots lodged in my lungs.

This Time

I can only blame my own body
Which is clotting/plotting against me.

**I dot,
therefore
I am.**

It Isn't IroniC

Written by: beecute

IroniC

I took myself out for Chinese food to
celebrate.

A Therapeutic INR.

Special Chinese Lunch Combo, only
\$6.50.

Green Tea, Egg Roll (full of Cabbage),
Chinese Vegetables.

Vitamin K, Vitamin K, Vitamin K.

I could only nibble my celebratory





Catastrophic Antiphospholipid Antibody Syndrome

Written by: Bruno Sainz

Hello my name is Bruno Sainz and I hail from Victorville, CA.

In 2005 my wife convinced me to give up my sedentary lifestyle and begin to exercise. After five minutes on the treadmill, I felt a sharp pain in my left leg. At first I dismissed the pain, as I thought maybe I pulled a calf muscle.

As the days went on my leg swelled so much I could not even put on my shoes. When I finally went to see the doctor, I was sent to the hospital to get an emergency ultrasound of my leg.

When the results came back I was told I had a blood clot in my leg and I would have to stay a few days in the hospital.

During this time the doctors ran what seemed to be a million tests and the diagnosis was "Lupus Anticoagulant Disease".

After a few weeks, I went home with heparin, warfarin and a million questions. A year went by and just as I thought the worst was over, I got another blood clot. No time in the hospital this time, just rest and more Coumadin® and a new diagnosis of Antiphospholipid Antibody Syndrome.

Again, about a year and a half later, I start having pain in my leg and swelling. After four visits to the ER and

numerous ultrasounds of my leg, a seemingly bewildered ER doctor advised I get a CAT scan of my chest.



Low and behold I had a pulmonary embolism. I was admitted to the hospital for treatment and instead of getting better I had a turn for the worse.

My liver and spleen were shutting down and I had began to show signs of jaundice. After meeting with numerous specialists, a new Rheumatologist came in and let me and my wife know that what I had was "CAPS" as it was visible from the numerous blood clots showing on the scan of my liver, spleen, and now my kidneys.

After massive doses of platelets, steroids, and blood, I made a recovery and left my hospital bed for home after almost 4 weeks. My platelet counts continued to be a concern so my Hematologist had me undergo a procedure called IV immunoglobulin, which he believed would help stabilize my platelet counts.

After four visits my platelet count has stabilized and things are much better. I have learned to live with INR tests, warfarin, steroids, and Plaquenil®.

To a better future for all us from a fellow "CAPS" survivor.

The APSFA Partners with the AARDA to Sponsor NCAPG Congressional Briefing

Written by: Cindi Brookes



As National Coalition of Autoimmune Patient Group (NCAPG) Members, we took the opportunity to partner with the AARDA to sponsor the Wednesday, March 28th Congressional Briefing "The Multi-Generational Impact of Autoimmune Diseases". It will be in Rayburn B-338 from 12 Noon to 1:15PM in Washington, DC.

As this program is presented by the NCAPG; it is imperative that we provide the financial support necessary to ensure that we can continue to bring important awareness messages to Congress on behalf of our cliental.

The full flyer for this event can be located here:

<http://www.apsfa.org/docs/ncapg-flyer-2012-color2.pdf>



Thirty-One Facts About Lupus

Submitted by: Tina Pohlman

With May being Lupus Awareness Month. We thought we would take some time to educate you on some Lupus facts.

1. Over 2 Million Americans have Lupus
2. Over 90% of those with lupus are women
3. Benlysta®, is the first new medication approved for the treatment of lupus, in over 55 years.
4. Aspirin was the only drug approved for lupus up until 1955 when Plaquenil® was also approved.
5. Children as young as infants are diagnosed with lupus
6. Children who are diagnosed with lupus have a higher rate of kidney involvement than those who are diagnosed in adulthood.
7. Lupus is more common than MS, Cystic Fibrosis, Cerebral Palsy, and Sickle cell anemia combined.
8. Lupus is NOT infectious, rare or cancerous
9. Although the cause of lupus is unknown, scientists suspect that individuals are genetically predisposed to lupus, and know that environmental factors such as infections, antibodies, ultraviolet light, extreme stress and certain drugs play a critical role in triggering lupus.
10. Lupus is more prevalent in African Americans, Latinos, Native Americans and Asians.
11. In an autoimmune disease like lupus, the immune system loses its ability to tell the difference between foreign substances and its own cells and tissues. The immune system then makes antibodies directed against "self."
12. Lupus affects 1 out of every 185 Americans and strikes adult women 10-15 times more frequently than adult men
13. Some symptoms of lupus can be transient joint and muscle pain, fatigue, a

rash caused by or made worse by sunlight, low-grade fevers, seizures, hair loss, pleurisy, appetite loss, memory loss, sores in the nose or mouth or painful sensitivity of the fingers to the cold.

14. Out of the 1780 people who participated in the Lupus Alliance (LAA) National Survey in 2010, 11% reported they had a cousin who also has lupus, 6% had mother's who also have lupus, and 5% had sisters who also have lupus.

15. The five most frequent symptoms in the LAA Lupus Survey are fatigue (93%), joint pain (92%), muscle pain (80%), headache (71%), and confusion/forgetfulness (70%).

16. Participants in the LAA National Survey also reported receiving a secondary diagnosis of what are commonly referred to as overlapping conditions. The most prevalent are arthritis (51.8%), Raynaud's phenomenon (44%), Fibromyalgia (36%), Anemia (31%), and Sjogren's syndrome (28%).

17. There is no single test to diagnose lupus. It may take months or years for a doctor to make a diagnosis of lupus.

18. The unique pattern of symptoms associated with lupus has caused some to say that lupus is like a snowflake. No two cases are alike.

19. Typical treatments for lupus include steroids, painkillers, anti-malarials, and immunosuppressants.

20. If left untreated, lupus is potentially fatal, due to organ damage and failure. Serious conditions that arise include kidney disease, pancreatitis, pleurisy, vasculitis, pericarditis, and cancer.

21. Lupus is one of America's least recognized major diseases. While Lupus is widespread, awareness and accurate knowledge about it lags decades behind many other illnesses.

22. More than 16,000 Americans are diagnosed with lupus each year.

23. Some of the factors that may trigger lupus include infections, antibiotics, ultraviolet light / sunlight, extreme stress, certain drugs, and hormones.

24. The majority of the symptoms of lupus are internal. therefore, it is hard to identify a person with lupus by outward appearance

25. Fatigue is a common symptom of lupus that is often misdiagnosed as depression or another disorder.

26. According to the LAA National Survey, The Majority of respondents reported that it took nearly 7 years from when they first experienced symptoms until the time of diagnosis.

27. From the LAA National Survey, over 75% of participants reported that they frequently need someone to take over or assist them with tasks or chores when they are not feeling well.

28. From the LAA National Survey, nearly 70% of those surveyed reported that their employment has been affected because of their lupus, with 36% stating they are no longer able to work.

29. According to the LAA National Survey almost 40% of the participants reported they were hospitalized in the past five years due to their lupus.

30. According to the LAA National Survey 30% reported that they had a blood relative who also had lupus.

31. Fifty percent of Lupus patients also have Antiphospholipid Antibody Syndrome (APS).¹

Resource:

The Lupus Alliance of America <http://lupusalliance.org/>. Last accessed March 12, 2012.

Fifty percent of Lupus patients also have Antiphospholipid Antibody Syndrome (APS).¹



(Continued from page 1)

InternatiOnal Networking, or **APS ACTION**.

The Mission of APS ACTION: The primary mission of APS ACTION is to prevent, treat, and cure aPL- associated clinical manifestations through high-quality, multicenter, and multidisciplinary clinical research. The secondary mission is to refine and advance the definitions of aPL-associated clinical manifestations through international collaboration and data sharing. The approach is that all the members work together through this research alliance to design and conduct clinical trials, collect data via an international registry, and leverage funding opportunities.

A Journey of Success from the Miami 2010 Summit to the Present:

Due to the hard work, regular meetings, and collaborative spirit of APS ACTION members, in early 2012, APS ACTION launched two important collaborative international projects: 1) a multicenter randomized controlled trial of hydroxychloroquine in the first blood clot prevention of persistently aPL-positive but thrombosis-free patients without other systemic autoimmune diseases; and 2) an internet-based registry of aPL-positive patients with or without systemic autoimmune diseases, which will also include annual blood collection for aPL-testing and future basic science studies. In addition, the APS ACTION website (www.apsaction.org) was launched this

year along with its identifying logo that have been used internationally. Since November 2011, APS ACTION has been accepting applications from new centers that can contribute to its mission. Membership has been decided based on well-defined eligibility criteria that include the APS research interest of centers and their commitment and ability to participate in APS ACTION research activities. Physicians interested in participating in APS ACTION network can contact Joann Vega CCRC, APS ACTION lead coordinator, at apsaction@info.org.

What Does APS ACTION Mean for APS

Patients?: Randomized controlled clinical trials require a large number of patients for clinically meaningful outcomes and APS ACTION network will help us study large groups of aPL-positive patients in a more organized way. As a result of this international effort, we will better assess the clinical characteristics of patients and also which aPL-positive patients are at increased risk for clinical problems. In addition, the international registry will be a valuable resource for future basic science and clinical research projects. For more information on APS ACTION and to how you can become involved in the APS ACTION network or clinical research studies, please visit www.apsaction.org or contact Joann Vega, CCRC, APS ACTION Lead Coordinator at apsaction@info.org.

Conclusion: Our hope is that APS ACTION

will support and promote aPL/APS research internationally by: 1) designing collaborative large-scale clinical research projects that will help generate evidence-based recommendations for prevention and management of aPL-related clinical events; 2) maintaining a repository that will help us standardize aPL tests and perform mechanistic studies; and 3) generating private and government funding all around the world.

In the end, we hope to find better treatments for APS, which is a leading cause of thrombosis, pregnancy morbidity, and other life-altering consequences, – and to heighten awareness about this life-threatening, autoimmune condition.

References:

Erkan D, Derksen R, Levy R, Machin S, Ortel T, Pierangeli S, Roubey R, Lockshin MD. Antiphospholipid Syndrome Clinical; Research Task Force Report. *Lupus* 2011;20:219-224

Erkan D, Lockshin MD, on behalf of APS ACTION Members. APS ACTION; AntiPhospholipid Syndrome Alliance for Clinical Trials and InternatiOnal Networking. *Lupus*, In press.

Please contact the [APSFA](http://www.apsfa.org) for full members & centers list.

2nd Annual Bowling for Jessica ~ In Loving Memory of Jessica Kidd Vogelpohl

Written by JeriAnn Kidd

All proceeds to benefit the APS Foundation of America, Inc.

Sunday, April 29th at LaRu Lanes in Highlands Heights, KY.

With proceeds from last year's event, The APS Foundation of America started the Jessica Kidd Vogelpohl Scholarship. This scholarship went to a medical student specializing in blood disorders from the University of Texas. We are hopeful this

yearly fundraiser will allow crucial testing to continue and spread awareness of CAPS and APS which took our Jessica.

Please bring you family and friends and join us as we celebrate Jessica's life. The family event includes bowling, food, raffles and fun. Cash bar is also available.

Adult fee \$10.00

Kids fee \$6.00

Bowling sessions:

11:00 to 1:00, 1:30 to 3:30, 4:00 to 6:00 and 6:30 to 8:30

Please email Joe and Jeriann for bowling session and any questions. glenn.kidd@zoomtown.com

If you would like to contribute a gift for our raffle, we would be so grateful.





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Online Support: www.apsforum.com

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 APS Foundation of America, Inc 
Antiphospho.....what?!?



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Café Press ~ DVT & Lupus Awareness Items



We have a number of new products & designs for DVT and Lupus Awareness Items available in our Café Press store. Some of our new products and designs are shown here and many are available in burgundy for APS as well. Our creative team is working on new one of a kind designs and lines and many more will be coming soon. There are even a few new items such as travel mugs, glasses, cellphone &

iPad accessories, pillows, and dark colored shirts and sweatshirts. Our Café Press 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>