ANTIPHOSPHO...WHAT?

APS Foundation of America, Inc. Newsletter

Volume 3 Fall 2006

The Winding Path ~ Dana's Story

Written by: Dana Stuart

On the outskirts of a desolate northwest Missouri town, there is an 11-acre haven that bears the fruit of hope and nostalgia. To embark upon its beauty is to instantly recall childhood dreams, to bask in the glory of the moment, and to renew your hope for the future. To get a better view, one must walk about the winding path. On this path you will find honeysuckle, wild flowers, and large areas of golden wheat. They represent the beauty of life, those bittersweet memories, and the wonderful milestones that await you. But nestled in the timber, you will also find thorny willow trees, snakes, ticks, and other painful forms of life. Little did I know when I began my journey to build a family with my husband, I would approach the sharpest of thorns, and ticks like no other that sucked the life right out of me. Little did I know our infant twins' first crib would be a tiny white casket; that I was suddenly living with a disease that took away my choice to have children and could take away my life at any given moment with little or no notice. It's called APS (Antiphospholipid Antibody Syndrome).

My story really begins in high school, when those maddening moments of headaches, fatigue, and dizziness gave me the label "hypochondriac." In my early 20's, after the birth of two children, I found myself on the couch quite frequently with the same symptoms and trying to explain it to my now ex-husband who thought I was just lazy. After many years and life changes, I found myself trying to conceive again. Who would have imagined this would be a problem? My first two children came so easily. Month after month, the tests would come back negative. Or worse yet, they were positive with nothing to be seen on the sonogram. It was two years into trying to conceive before anyone suggested I be tested for APS. In May of 2003 I received the diagnosis of APS. In January of 2005 it was confirmed again. The disappointment surmounted and the emptiness began to take its toll. I was placed on Heparin and aspirin, but this alone did not work for me. There was only one treatment left to try, In Vitro Fertilization.

In July of 2005, we had finally saved enough money to do the IVF. The shots began. One by one, I jabbed myself into looking like a pincushion. On July 20th we retrieved over 30 eggs. Five days later, two embryos were transferred back into my uterus, and on August 4th I found out I was pregnant. I absolutely couldn't believe it. I must have purchased 10 home pregnancy tests that day just to be sure. Two weeks later, we received the wonderful news. We were having twins.

A lack of understanding of APS, however, led to improper treatment. While the standard treatment for APS during pregnancy is Lovenox and Aspirin, I received steroid treatment. Twenty weeks into the pregnancy, I gave birth to a beautiful baby boy and baby girl, Andrew and Hannah, who died 3 ½ hours after birth. I later read several medical journal articles that stated steroid treatment increases maternal and fetal morbidity and was told by many doctors I should have been on Lovenox and Aspirin. How discouraging to find the right treatment after it's too late.

Today I am still picking up the pieces. As I walk about the winding path, I remember Andrew and Hannah. With great joy and with great sadness, I tell others about them, and about APS. In doing so, Andrew's and Hannah's lives were not a waste.

As I continue my journey through this grief, and learn to live with the effects of APS, I realize that without APS awareness, I have no hope for positive pregnancy outcomes. With awareness, I can have hope. Not only for a healthy pregnancy but a long and healthy life. Won't you please join our efforts?

"The sun shines not on us, but in us." - John Muir

Favorite quote of Kathi Harpst, forum member

Friends of APSFA

Do you believe in our cause? If you do, you can now become a "Friend of APSFA". For a membership fee of $25.00 you will get our Friendship package which includes:

- Our quarterly newsletter in paper form
- 1 year 'sample' Anticoagulation log book
- Printed copy of all our Brochures
- APS Awareness pin
- Priority for answers with our "Ask A Doc" page

If you would like to become a "Friend of APSFA" please visit our website for how to do so. More information is located at www.apsfa.org/friends.htm.

We Need Your Help!

We are in search of patient stories and Newsletter articles. If you would like to contribute something, please email us at articles@apsfa.org

We are also searching for doctors who are currently treating APS patients for our Dr. List. Please see our website for more details.

Inside this issue:

Letter from the President

Fall is upon us already before long we will be getting ready for Christmas. Where has the time gone?

Since this is the start of the season of giving, The APS Foundation of America, Inc. is asking you to please consider us for your end of the year contributions and / or holiday donations. We are the first and only foundation in the United States dealing specifically with APS, and one of only two in the world. If you or your company are looking for a charity to donate to, please consider the APS Foundation of America, Inc. We are a non-profit organization therefore all donations are tax deductible. If your family has ever been touched by heart attack, stroke, pulmonary embolism, or pregnancy/infant loss, our foundation welcomes you to join us as well. Without your help the Foundation, its support forum, and awareness could not happen. When we started this, we honestly thought we could run this on a couple thousand dollars. In reality, we need closer to $10,000.00 a year to run it on a national level rather than locally, with postage, professional fees and printing costs being the biggest expenses for us right now. We can not continue the level of service we provide without your help. We are trying very hard to keep the cost to the consumer free.

The APS Foundation of America is actively working with our medical advisors and their respective facilities to get the education out about APS. We have been contacting various newspapers and media sources to get the word out about APS and the foundation. We are contacting area hospitals and providing them with needed patient information, memorial items for bereaved parents, organizing educational conferences, awareness walks and in the planning stages of setting up physical support groups around the country.

The Discovery Health Channel (DHC): Mystery Diagnosis has re-aired several times and can now also be found on The Learning Channel (TLC). Please check your local listings for the next air-date.

Once again, I hope this newsletter finds you in the best of health and with a perfect INR level. Wishing you and your family a wonderful holiday season and healthy and peaceful New Year!

Sincerely,

Tina Pohlman
President & Founder

APSFA Board of Directors

PRESIDENT
Tina Pohlman, WI

VICE PRESIDENT
Heidi Ponagai, MI

SECRETARY
Todd Ponagai, MI

STEERING COMMITTEE
Dana Stuart, MO
Elaine McGonagle, NH
Kathi Harpst, KS
Lyndal Parker-Newlyn, FRAGCP, AU
Tom Schwab, TX

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
Associate Staff, Georgetown University Division of Rheumatology/ Immunology

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

Al Lodwick, RPh, MA
Certified Anticoagulation Care Provider
Founder of the Warfarin Institute of America

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

Virginia Tekieli
Clinical Pharmacist, Anticoagulation Pharmacy, Department of Pharmacy
Harper University Hospital, Detroit, Michigan

R. LaDonna Hinch, RD
Nutrtionalist
Karmanos Cancer Center, Detroit, MI

Gerald T. Simons, MPAS PA-C
Clinical Instructor
Cornell University Weill Medical College

TIA, Migraine Or Stroke? When Do You Go To the ER?

Written by: Associate Professor Lyndal Parker-Newlyn FRACGP

"When to go to the ER" is a really hard question. It would be easy to say "ALWAYS" but in reality, it depends where you live, what access to health services you have, what previous positive or negative experiences you've had with ER treatment, how stable you are, and what medications you're on.

> **"The last episode I thought was a TIA but I put up with it for 4 hours...it was not a TIA, but a stroke"**

I'll see if I can put it into some kind of logical algorithm, but it is still a personal issue

1. If you are stable, and you are having an event that is short, limited, typical for you, **and** resolves completely then you probably don't need to go, especially if everything else is stable (I recently had a 15minute episode of visual disturbance - left sided typical TIA for me - INR was fine, on high dose steroids, nothing would have changed ...so I didn't go, but I made sure I rang my specialist, checked with him and let him know).

BUT...

2. Anything that goes on for **longer** than usual needs to be investigated (my TIAs are dramatic but short- if it lasts more than 45 minutes then I'm scared!! The last episode I thought was a TIA but I put up with it for 4 hours....stupid stupid stupid...it was not a TIA, but a stroke).

3. Anything that is **different** for you needs to be seen. Again that last one for me was different - I usually have amaurosis fugax or even complete visual loss on the left in my TIAs and they come and go fast. The four hour one was completely different – vomiting, vertigo, clumsiness - I should have gone to ER when it felt wrong.

4. Anything that happens and you are **not adequately** anticoagulated - your INR is too low or you are not on warfarin/aspirin or lovenox - must be seen at the ER, as the risk of it being a stroke rather than a TIA is high. Also remember, even with a therapeutic INR, a stroke is still possible when you have APS.

5. Anything that affects your **level of consciousness** rather than just physical symptoms MUST be seen. If you are vague, drowsy, confused, or sleepy on top of the vision change or numbness then take it VERY seriously It could be direct effects of APS on your brain or it could be the beginnings of catastrophic APS, uncommon but very dangerous.

6. The big one—**if you are scared...go to the ER**. Don't wait around. Worst possible scenario is you waste a few hours. But if it does progress and you are having a stroke then better to have it there than in your lounge room.

Use this opportunity to talk to your doctor when you see them next about when YOU should go to the ER. Have a clear action plan in place so you feel confident of when you need to be seen. And remember if you do need to go to the ER, take as much information as possible with you. Your APSFA log book is an ideal place to start.

Alternatives To Warfarin

Written by: Al Lodwick, RPh, MA

This issue will start a new series about medications. We will start off with looking at medications that are possible replacements for Warfarin. A few years ago there was a drug called Exanta (ximelagatran) that was touted as the replacement for Warfarin. However, an FDA Advisory Committee recommended against approval in September 2004 because it caused liver failure and death from uncontrollable bleeding. The company has abandoned all attempts to bring this drug to market.

The next drug that will try to displace Warfarin is likely to be dabigatran which will go by the brand name Rendix. In the BISTRO I study people with total hip replacements took various doses to determine which one would be the most effective. There was some bleeding among the people who took 300 mg. The BISTRO II study tried to determine how well various doses worked. Again there was a statistically significant increase in the risk of bleeding at the 300 mg level so the dose will probably be less than this. Evidently there will have to be some studies to find a balance between clot prevention and risk of bleeding. No other studies have been published.

There is some hope that the drug will be on the market by 2008, but it seems to me that 2009 or 2010 is more realistic.

One important point to note is that there is no drug currently in clinical trials that will replace Warfarin in the treatment of APS. As of yet APS is not understood down to the molecular level. This understanding is a major step in being able to develop a drug specifically for a disease. Until that is understood, and therapy specifically targeted at APS remains more than ten years away.

It may turn out that dabigatran is a better treatment than Warfarin for APS, but it will be more of an accident than by design.

Warfarin remains the standard of care for APS even though it was discovered somewhat by accident more than sixty years ago. As far as long-term toxicity goes, Warfarin is fairly safe. I know of a person who has been on it for most of forty-six years and several others who have taken it for more than thirty years. For the most part, they do not have liver disease, kidney disease, nor osteoporosis. These are major concerns for people who take medications long-term.

Further updates on dabigatran will be posted as they become available on my website at www.warfarinfo.com/dabigatran.htm.

"I have come to be grateful for and appreciate is the experience, strength and the hope that forum has provided through individual stories, help. In fact, I am suggesting that my physician check out the national APS website."

-APS Friends & Support Forum Member Testimonial, Houghton, Michigan

Different Ways To Donate To The APSFA This Coming Holiday Season

Written by: Heidi Ponagai

The 2006 Holiday season is right around the corner and sneaking up on us faster than you think! Now is the perfect time to start thinking about where your holiday charity donations are going this year. This page is going to be dedicated to the many different ways you can donate to the APS Foundation of America, Inc. during the holiday season as well as the rest of the year.

APSFA Online Giving Tree

The APS Foundation of America, Inc. is going to have a "Giving Tree" this year. We will be "planting" a large Christmas tree on our website and will be trimming the tree with your donations.

Each decoration on the tree will represent a donation. There will be different colored ornaments to represent different dollar amounts, as well as presents, stars and other Christmasy items.

The donor's name (first initial, last name) and location will be visible when someone moves the mouse over the ornaments. If you'd like your donation to be anonymous, we can put that as well.

Donations made in memory or in honor of someone will have a different shape and/or color and will also included the person's name the donation was made for.

We will be putting more information about the "Giving Tree" on our website soon, and we will be "planting" the tree in early November.

Other organizations have had much success with their "Giving Trees" and we hope that we will as well!

All donations to the "Giving Tree" will be tax deductible.

Please watch our website for more information!

The APSFA CafePress Online Store

We have a wide selection of APSFA, APS, DVT, Lupus, FVL, and thrombosis gear located on our CafePress online store.

With every item purchased, the APSFA receives a small donation. We have made over $400.00 so far in 2006 just with CafePress sales!! Thank you to everyone who's purchased our items!

For those people who are not familiar with our store, we have items like t-shirts, sweatshirts, teddy bears, aprons, buttons, magnets, and stickers, just to name a few. We also sell a lot of our APS log books which are a great tool for any APS patient. They are great to bring to appointments because all the information you need is right there.

New for the holidays, we have our exclusive APSFA Keepsake ornament. We have picked a snowflake to adorn our ornaments because all snowflakes are different, just like every APS patient is different. The ornaments are $8.00 each and are made of porcelain.

Check out our store online at www.cafepress.com/apsfoundation to buy APS gear and help the APSFA at the same time!

Other Ways to Donate

There are many other ways of donating to the APSFA this holiday season.

- We accept donations in honor or in memory of family, friends, or loved ones.
- You can print a donation sheet from our website, or send us donations via PayPal online. We accept personal checks and money orders and credit card donations through PayPal.
- On our website we have burgundy ribbon lapel pins, postcards, and APSFA pens for sale. All profits of these sales go to the foundation.
- We also have joined Mission Fish and people can now donate to us with their eBay auctions. In the upcoming months we will be selling things under the eBay name of 'apsfa'. 100% of the monies earned from these auctions will go towards the APSFA.
- You can become a sponsor of the APSFA website and / or APS Friends & Support forum. These types of sponsorships are $20.00 per month, per site. The sponsor's name(s) will be posted on the foundation site or the forum. We have had much success with this and were able to get monthly sponsors for most of 2006. We do have all of 2007 open, so act now if you'd like to sponsor a certain month!

- We also have continous monthly donation "subscriptions" available in the amounts of $10, $15, $20, & $25 per month for one year. These can be done by PayPal, or by check if you wish. Contact us for more details.

All donations made to the APSFA are tax deductible and we send out receipts for all donations we receive for tax purposes. Please see our website for more information on making donations to the APSFA. www.apsfa.org/donate.htm

Please be sure to have all donations for 2006 post dated by 12/31/06.

Without your donations, the APSFA would not be able to survive. We greatly appreciate each one of our donors.

Antiphospholipid Antibody Tests-Once Is/Is Not Enough?

Written by: Gale A McCarty, MD, FACP, FACR

The Problem of Laboratory Tests in APS. Despite many years of growing awareness of the antiphospholipid antibody syndrome (APS) and the enormous body of work by dedicated clinical and basic researchers to provision of the optimal laboratory tests for all patients, challenges still face the ordering physician.

Test Sources and Choices. Many clinicians have the choice of tests or test kits used by regional referral laboratories contracted by their healthcare system, and represent the majority of physicians nowadays. Other clinicians order in-house tests or test kits where they may have been more involved (with their Departments of Laboratory Medicine) in helping to define performance characteristics by joint oversight or by providing sera/plasma samples from well-characterized patients to assess test precision and accuracy. Lastly, the minority of clinicians have experts in-house who have developed APS tests, and they provide this expertise onsite. Both these experts and many commercial lab test or test kit manufacturers have voluntarily participated in the Kingston aPL Study Group or International Coordinating Committee-organized inter-laboratory wet workshops and exchanges overseen by E. Nigel Harris MD, DPhil, and others on these Committees. These workshops helped to determine the most commonly used test units and their ranges from negative to positive in large populations of patients and controls. For IgG aPLs, these are called GPL units, for IgM aPL, these are MPL units, and for IgA aPLs, they are APL units. This is the source of the phrase seen in many laboratory test manuals and package inserts for aPL enzyme-linked immunosorbent assays (aPL ELISAs) that "Harris Standards" were used.[1] Other laboratories use other cut-off values.

The coagulation-based tests ("Lupus Anticoagulant-LAC, or Dilute Russell's Viper Venom Test-DRVVT) are "standardized" in in-house or commercial tests or test kits according to the International Society for Thrombosis and Haemostasis recommendations, and these results are expressed only as positive or negative values, and not stratified from lowàhigh levels as are aPL ELISAs.

Variation in Test Results for APS. Test results on patients' samples vary for a lot of different reasons: a) inter-laboratory correlation of the same test may vary, even with the same protocol and patient sample; b) patients may have serial tests performed by different laboratories which use different classifications from negativeàhigh positive levels, and most importantly, c) the tempo of the disease or the effects of treatment may vary on an individual basis and contribute to changing levels of autoantibodies.

A recent analysis of laboratory data from aPL positive patients in two large data bases: a) the National APS Collaborative Registry (APSCORE), and b) APS prevention with aspirin-the APLASA study-from the Hospital for Special Surgery in NY provides some interesting insights on analysis of 1652 lab tests.[2]

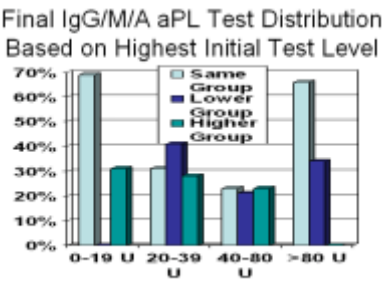


Fig. 1. Data replotted from Erkan et al: Ann Rheum Dis 64:1321-5 '05

In this study, 81 patients met Sapporo Criteria for APS (57 with vascular events with or without pregnancy events, and 24 with pregnancy events only) and 123 just had positive aPL tests without any vascular or pregnancy events. The study patients were 93% female, 71% white, 10% Afro-American, and had a mean age of 45.9 +/- 13 yrs at Registry entry. The test ranges for aPL ELISAs used were: negative = 0-19 Units, low positive = 20-39 Units, moderate positive = 40-80 Units, and high = > 80 Units. The tests used included both an in-house standardized method and at least one commercially available test or kit. The ranges are very reasonable cut-offs based on most workshop data, but there is not a universal agreement about all boundaries. As with most tests, the low-positive and moderate-positive levels are the most troublesome to pin down. For simplicity, no LA test results will be discussed herein.

IgG/M/A aPL ELISA Results. For the aCL results in this study on the 179 patients who had more than 1 test, the number of patients classified at entry by their highest initial test were 42 (aCL negative), 51(aCL low positive), 39 (aCL moderate positive), and 47 (aCL high positive). A more detailed analysis of the stability of the test results over time (defined by the Authors as whether the test results were still in the same groupings (highest initial test U) at the last test is graphically seen in Figure 1, based on the final results. The Y axis shows the percentages of tests comparing all aCL ELISA isotypes; the X axis shows the aCL test levels. In- house tests accounted for 58%, 36% were done by one of two commercial lab tests/kits, and 6% by the APSCORE assay. The graphs show a tendency toward stability in the negative and high positive ranges (69% and 66% respectively), while 54% of those in the moderately positive range dropped to a lower range. For the low pos group, 41% had a final aCL in a lower group. The sources of the tests or test kits are defined in the accompanying text. In presenting total subsequent aCL results (as a measure of stability of the aCLs based on the 4 groupings from normalàhigh, 59% of aCL negative, 53% of aCL low positive, 50% of aCL moderate positive, and 74% of aCL high positive patients remained in the same group.

Anti-ß2gpI ELISA Results. For anti-ß2gpI results in this study on the 27 patients who had more than 1 test, aggregated levels were used: 0-39 U for normalàlow positive, and >40 U for moderateàhigh positive. Figure 2 shows these results with the Y axis showing the percentages of tests comparing all isotypes, and the X axis showing test levels. Commercial tests/kits were used in 54%, 37% were done by the APSCORE test, and 9% used other labs. For this test, 92% of the normalàlow positive patients and 73% of the moderateàhigh positive patients had their final test in the same group. The stability measures here for total results were 96% and 76% remaining in the same group, respectively.

Overall aCL Test Considerations. To assess inter-laboratory test variation, the authors looked at patients who had aCL testing done on the same samples by in-house assays and commercial labs/kit suppliers. Consistency (the % of results within the same group) ranged from 64% to 88% across all the combinations, the agreement between the aCL groups was only moderate for IgG/M vs IgA isotypes, and the correlation (measure of the direction and strength of how the tests compared) ranged from 0.5 to 0.8. These results are not dissimilar from other inter-laboratory wet workshops and sera/plasma exchanges, and show that there is still work to be done; others have found the agreement for aCL

Article continued on pg 6

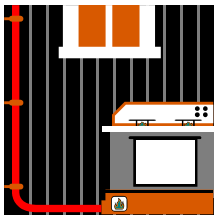
Carbon Monoxide Poisoning

Written for: Prevention Connection, Gundersen Lutheran

Each year in the United States, it is estimated that 500 people die and an additional 5,000 are treated in hospital emergency rooms because of carbon monoxide (CO) poisoning. CO is a toxic gas that has no odor, taste or color. CO is produced as a result of incomplete burning of carbon fuels like wood, coal, fuel oil, charcoal and natural gas. High levels of CO interfere with the body's ability to distribute oxygen to vital organs and tissues and can be lethal.

Symptoms of CO poisoning

- Mild headaches
- Dizziness and nausea
- Confusion and disorientation
- Impaired coordination
- Unconsciousness that can potentially lead to death



If you think you have CO poisoning

- Get fresh air immediately
- Shut off all fuel burning appliances
- Open doors and windows to allow circulation of oxygen
- Go to a hospital emergency room and let them know you may have CO poisoning

CO poisoning can be prevented with regular maintenance, inspection and proper ventilation of fuel burning products like non-electric furnaces, gas water heaters, fireplaces, wood stoves, gas stoves, dryers, charcoal grills and automobiles. Also consider investing in a CO monitor for your home.

Source: PRevention Connection; Gundersen Lutheran Vol. 5, Issue 1, Spring 2006, Page 4

Did You Know...?

The 12th International Symposium on Antiphospholipid Antibodies (12th ISAPA) will be held from April 18 - 20, 2007 in Florence, Italy. The program will address all clinical/basic research and treatment aspects of APS, and includes a session for patients. Further details can be found at: www.antiphospholipid.net.

- Submitted by Dr. McCarty, Member, Int. Adv. Board for ISAPA for the meeting Co-Chairs Dr. PL Meroni and Dr A Tincani.

...APS Tests article con't...

tests to be in the medium range.[3]

Conclusions. This study reflects some of the realities of the ordering physician in the "real world", where multiple test sources may have to be used. Its use of two very large databases of patients with well-defined and standardized tests is laudable. However, entry of patients into registries is voluntary, may have biases from region to region, and thus may be a "slice of the pie" and not always applicable to the entire population.

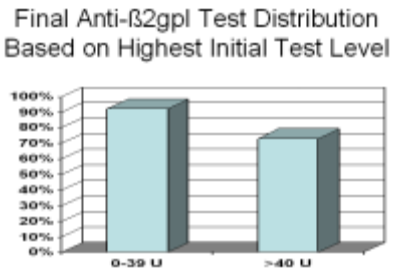


Fig. 2. Data replotted from Erkan et al: Ann Rheum Dis 64:1321-5 '05

While some standard treatments for APS are listed in their demographic analysis of the three groups of patients who represent a wide spectrum of aPL- and APS-related diseases and features, the drug treatment data is not detailed in terms of duration or relation to the first/last lab test results and is mostly pertinent only to one of the patient groups (vascular and pregnancy events). Hydroxychloroquine usage data is not even listed in the clinical characteristics table (Table 2) of the 204 patients (the % of patients with ACR-criteria diagnosable SLE ranges from 37-58% across all 3 groups so a reasonable use of this drug would be expected), yet a chi square analysis appears in the text that this drug has no relationship to test values in their study. Usage data was shown for aspirin and Warfarin in Table 2: neither of these drugs seemed to relate to test levels. (In a prior cross-sectional study from this group, the probability of an APS-related event was decreased by taking aspirin or hydroxychloroquine).[4] Thus conclusions from expert groups of investigators culled from a variety of patients with different treatments may yield different results than studies from patient populations meeting the same Sapporo and ACR criteria treated in exactly the same way throughout the study period. Treatment and SLE activity likely do have an effect on aPL variation, and this, as they appropriately cite in the discussion, remains an unsettled matter.

This study, while well-done in many aspects, was not designed or powered to answer these questions. It is a "look-back (retrospective) analysis of patients followed, as opposed to a "look-forward" (prospective) study with the same treatments being used. Our work on 250 patients with APS prospectively followed on aspirin and hydroxychloroquine therapy was associated with a mean of 3.38 mo (+/- s.d 0.93) to aPL decrease, and a mean of 5.68 mo (+/- 0.46 s.d.).[5] The authors state their "take-home" message is that 75% of aPL results remain stable for the ranges of negative-low and moderate-high over time, this study also shows that these high percentages of stability are not met for the low and moderate level patients, where a lot of the diagnostic/classification dilemmas occur. It is important to interpret tests in light of the patients' entire medical history, and relevant family history, which is always a good approach, as it is a combination of clinical features and supportive lab test results that is best.

For both ordering clinicians and the patients who as partners in their care with us continue to kindly provide us specimens because of their symptoms, a periodic evaluation of their tests for general trends or an assessment of therapy, the exact interval at which tests should be repeated is still not crystal clear at this time, and thus "once may not be enough". We still have work to do together.

1. Harris EN, Pierangeli SS: Revisiting the anticardiolipin test and its standardization. Lupus 11:269-75, 2002.
2. Erkan D, Derksen WJM, Kaplan V et al: Real world experience with antiphospholipid antibody tests: how stable are results over time? Ann Rheum Dis 64:1321-1325, 2005
3. Audrain MA et al: Comparison of different kits in the detection of autoantibodies to cardiolipin and beta-2 glycoprotein I. Rheumatology (Oxford) 43: 181-5, 2004.
4. Erkan D et al: A cross-sectional study of clinical thrombotic risk factors and preventative treatments in APS. Rheumatology 41:924-29, 2002.
5. McCarty GA, Cason TE: Use of hydroxychloroquine in APS at 3 academic rheumatology units over two years: improvement in antibody titer and symptom management. VIIth Int. Congress on SLE Abstract Proceedings #M17A, 2004.

Health Tips for People with Antiphospholipid Antibodies

Written by: Laurel Ericson & Thomas L. Ortel, MD, PhD

People with antiphospholipid antibodies (aPL) have an increased risk for developing blood clots. It is important for people with aPL to stay healthy, and here are some points to follow that can help reduce the risk of developing blood clots.

Have regular check ups with your doctor and keep your appointments. Ask your doctor questions about the antiphospholipid syndrome (APS) and make sure you clarify any treatment instructions you do not understand. If you are taking anticoagulants, keep your appointments to get your blood tested and stay in regular contact your health care provider. As you and your health care provider are learning the ideal medication management for your body's needs, ask questions and be proactive in your health care.

Kick the smoking habit! Smoking increases your risk of a variety of health problems, including cardiovascular diseases such as strokes and heart attacks. Some studies have also found that smoking may increase your risk for a deep vein thrombosis (DVT) or pulmonary embolism (PE).

If you're a heavy smoker, begin on the path of quitting by reducing the daily amount of cigarettes you are currently smoking. If you smoke a few cigarettes a day, quit altogether! Quitting smoking greatly reduces the risk of stroke and heart problems. Replace cigarette smoking with chewing sugarless gum or candy. Tell everyone you're quitting smoking, so if you began to pick up the habit again, friends and family can hold you accountable to your anti-smoking commitment. Ask your health care provider for ways to stop smoking.

Maintain a healthy weight. Obesity, similar to smoking, is associated with a variety of health problems, including an increased risk for DVT or PE. Several studies have reported that individuals who are obese have a 2- to 3-fold increased risk for venous thrombosis. This issue is very important, given the increasing problem with obesity in the United States today.

If you are overweight, even losing just a small amount of weight will be beneficial for your health. Aim for a small goal that can be reached, like losing 5 lbs, instead of unrealistic goals of losing 25 lbs or more. Start small; people are more likely to stay committed to their weight loss goals if they seem practical and possible, so start with a goal to lose 5 lbs if you're overweight.

Whether you are overweight or at a healthy weight, incorporate physical activity into your daily routine. A great place to start is by taking daily walks. Walking is an inexpensive way to exercise that does not require any expensive equipment or athletic training. When you are exercising, take water with you to prevent becoming dehydrated. Bring your dog or a friend with you to help you stay motivated.

Immobility, either sitting or lying down for extended periods of time, can put some people at risk for developing blood clots. This could be sitting in a crowded airplane flying across the Atlantic ocean, or prolonged bed rest after a surgery or injury.

On long trips, be sure to exercise your legs by walking and moving every few hours. If you cannot move around, elevate your legs and change sitting positions often. Avoid crossing your legs for long periods of time while sitting down. During plane flights, drink plenty of water to avoid becoming dehydrated and do not drink alcoholic drinks. Some patients might benefit from a single dose of an anticoagulant ('blood thinner') such as a low-molecular weight heparin, prior to particularly long plane flights. If you do have an increased risk for a blood clot, ask your doctor about the best way to prevent a blood clot in your particular situation.

Remember not to take a vacation from a healthy lifestyle! Pass on large portions of fattening foods and seconds on dessert. Walk as much as possible. And, if you are taking a medicine such as Warfarin (Coumadin®), make sure you check with your doctor about the best way to manage the medicine while you're on your vacation. You want to have fun, but also be safe!

Precision BioLogic Is In Need of Your Plasma

Written by: Sandy Morrison & Heidi Ponagai

The APSFA is currently working with a company called Precision BioLogic and they are looking for people who are positive with the Lupus Anticoagulant (LA) to donate plasma.

Your blood plasma is urgently needed to make diagnostic kits safe and effective. We are recruiting donors who have tested positive for Lupus Anticoagulants.

How you can help? It's easy!! The following steps will explain how:

Step 1—Ask your doctor if it is OK for you to donate plasma. Thousands of people donate plasma everyday – it's easy and safe.

Step 2—Contact Sandy at Precision BioLogic at 1-800-267-2796, extension 237, and tell him you would like to donate plasma. Your confidentiality is assured.

Step 3—We will make arrangements to have a sample of your blood taken at a blood collection center near you. Your sample will be tested and you will be informed if you have been selected to be part of our donor program.

Step 4—If you are selected, we will make arrangements for you to donate your plasma and you will be generously paid for your donation.

Step 5—Smile because you have helped hundreds of people like you receive accurate blood test results.

Precision BioLogic manufactures many of the tests used by physicians to diagnose blood disorders. We use blood plasma as the basis for many of our products. Since 1992, Precision BioLogic has relied on donors like you to make some of the highest quality tests available.

For more information please visit our website at

www.precisionbiologic.com

PrecisionBioLogic
Quality System Registered to ISO 13485

APS Foundation of America, Inc.
Post Office Box 801
LaCrosse, Wisconsin 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

Find us online!
www.apsfa.org

APS Foundation of America, Inc.

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

Do you send fresh flowers to family, friends, or other loved ones?

The APS Foundation of America, Inc. has their own flower store!

http://apsfa.flowerpetal.com

Now when you order flowers at http://apsfa.flowerpetal.com, 12% of each purchase goes to the APS Foundation of America, Inc.

There are no additional fees for delivery – including same day delivery. This means you can save up to $12.95 compared to other on-line florists. So every purchase puts a smile on many faces – including yours!

Now is a great time to start sending out holiday arrangements!! So, check out our site and support the APSFA at the same time.

Tell everyone about apsfa.flowerpetal.com and help us make a difference.