



# ANTIPHOSPHO...WHAT?

APS Foundation of America, Inc. Newsletter

Volume 7

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*The APS Foundation of America, Inc. Board of Directors would like to wish all of our volunteers, donors, friends, and those individuals who have contributed to the success of this Foundation*

## *A Joyous Holiday Season!*

### **Advice For Reducing Holiday Stress**

Submitted by: **Todd Ponagal**

Crowded bustling malls, repeated trips to the airport to fetch long-lost relatives, and the constant shuffling of cookies and turkey out of your oven can translate into one reaction: stress. Christmas may be the season of love and celebration, but sometimes holiday festivities can become overwhelming.

According to Dr. Gail Saltz, a psychiatrist at NewYork-Presbyterian Hospital/Weill Cornell Medical Center, some families feel stress from trying to keep up with the Joneses. For others, family conflicts arise from stress borne out of togetherness. Additionally, mothers often do a tremendous amount of preparation during the holiday season. This excess work and struggle to please everyone can leave them feeling isolated.



"During the holidays, our lives become even more stressful as we try to juggle our usual responsibilities with extra holiday preparation and complicated family dynamics," says Dr. Saltz. "This year, try to keep your holiday stress to a minimum by prioritizing what is important to you and then planning how you will get it done."

- **Don't wait for the last minute to make plans.** If you have family difficulties, try to plan some time with friends.
- **Don't be a perfectionist about the holidays.** Prioritize the events that matter the most to you and your family.

Understand that you can't do everything, so choose the things that you can accomplish and enjoy.

- **For gift shopping, remember that it's the thought that counts.** Don't let competitiveness and perfectionism send you on too many shopping trips.
- **Simplify.** Don't bake 20 different types of cookies unless you enjoy it. You and your family may enjoy fewer cookies but more time together.
- **Remember that family time can be both wonderful and anxiety-provoking.** Sometimes, expectations for reunions are too high, resulting in disappointment and frustration. Try to be realistic.
- **Plan your time so that you take care of several errands on one trip.** You will have more time to spend doing the things that you really want to do.
- **Take some time to think about what the holiday really means to you and your family.** Time together, religious observance, reflection on your life and future goals – let these aspects of the holidays keep things in perspective.

These tips can help you to reduce stress and make the holidays a pleasure. Doing less may help you to enjoy the season more and that is really the best stress reliever of all.

NewYork-Presbyterian Hospital/Weill Cornell Medical Center 525 East 68th Street, Box 144 New York, NY 10021 NewYork-Presbyterian Hospital/Columbia University Medical Center 627 West 165th Street New York, NY 10032 <http://www.nyp.org>

Source: <http://www.medicalnewstoday.com/articles/32855.php>



### **Friends of APSFA**

Do you believe in our cause? If you do, you can now become a "Friend of APSFA". For a 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
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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](http://www.apsfa.org/friends.htm).

### **We Need Your Help!**

We are in *need* of patient stories and Newsletter articles. If you would like to contribute something, please email us at [articles@apsfa.org](mailto: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.

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## Letter from the President



Fall has already left us. I hope everyone had a wonderful Thanksgiving. Now to take on Christmas & New Years. Where has 2007 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, it support forum and awareness could not happen.

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

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## Traveling and Deep Vein Thrombosis

Submitted by: Tina Pohlman

For some people, prolonged periods of immobility may increase the risk of deep vein thrombosis blood clots forming in the legs. Although the causes are not yet fully understood, the condition is not confined to air travel and has been found in all forms of travel as well as non-travel situations such as theater seating. Deep vein thrombosis can cause pain and swelling in the legs both in-flight and for several days or weeks following travel. While these clots are not serious in and of themselves, if they break off and float to the lungs, they could result in a lethal pulmonary embolism.

bolism.

Here are a few simple tips that can increase your comfort and your ability to move around:



- Wear loose clothing and avoid tight, restrictive garments.
- Place as little as possible under the seat in front of you so you can stretch and periodically exercise your feet and ankles.

• Drink water and juice, and minimize alcohol and caffeine to avoid dehydration.

• Walk about the cabin every 60-90 minutes if flight conditions permit.

• Wear medical grade compression stockings.

• Consult your physician if you have health-related concerns about travel, particularly if you have underlying illnesses such as coronary artery disease, cancer, or a blood clotting disorder.

Source: Delta Airlines, Inc.

## Predicting Thrombosis Risk in Individuals with Antiphospholipid Antibodies

Written by: Thomas L Ortel, MD, PhD

Some individuals with antiphospholipid antibodies never have a thrombotic event, whereas other individuals have recurrent clots even when they are taking appropriate anticoagulant therapy. Unfortunately, we do not have laboratory tests or clinical findings that clearly identify those individuals at highest risk for forming a clot. Certain tests are more predictive than others, however, and newer tests may help identify these individuals even more accurately.

**“...several studies have shown that the presence of a lupus anticoagulant in the blood is associated with a higher risk for a clot than the presence of an anticardiolipin antibody.”**

Of the laboratory tests used for identifying antiphospholipid antibodies, several studies have shown that the presence of a lupus anticoagulant in the blood is associated with a higher risk for a clot than the presence of an anticardiolipin antibody. For patients with anticardiolipin antibodies, an IgG anticardiolipin antibody is more likely to be associated with a clot than an IgM anticardiolipin antibody, and a higher level of the antibody is also more problematic than a lower level.

More recently, anti-beta-2-glycoprotein I antibodies have been shown to be more frequently associated with clotting prob-

lems than anticardiolipin antibodies. One study reported that the presence of a lupus anticoagulant and an anti-beta-2-glycoprotein I antibody together was associated with a higher risk of clots. As with anticardiolipin antibodies, the IgG type is considered to be more problematic than the IgM type.

Other tests have been used to look for individuals at high risk for a clot, including the d-dimer, which is a breakdown product from cross-linked fibrin clots (the final blood clot). Persistently elevated d-dimer levels may be associated with an increased risk for thrombosis. More recently, thrombin generation tests have also been used, which are a measure of how much thrombin can be potentially generated in a patient's blood sample. Generating a higher amount of thrombin, which is the molecule that converts fibrinogen in the circulation to a fibrin clot at the site of an injury, in this assay is associated with an increased risk for a recurrent blood clot.

We have also been interested in this problem, and have used gene expression stud-

ies to compare patients with antiphospholipid syndrome and blood clots to individuals with elevated antiphospholipid antibody levels but no clots. We used blood samples and looked at all of different genes that were making messages in the different cells in the blood. We found that we could distinguish these two groups of individuals using this approach, and are continuing to work on this problem with more patients.

In conclusion, some tests may help to identify a person with antiphospholipid antibodies who is at risk for forming a new or a recurrent blood clot. These tests are not perfect, however, and need to be interpreted carefully and in the context of how the patient is doing overall.

### References:

M Galli, D Luciani, G Bertolini & T Barbui. Lupus anticoagulants are stronger risk factors for thrombosis than anticardiolipin antibodies in the antiphospholipid syndrome: a systematic review of the literature. *Blood*. 2003;101: 1827-1832

de Groot PG, Lutters B, Derksen RHWM, Lisman T, Meijers JCM, Rosendaal FR. Lupus anticoagulants and the risk of a first episode of deep venous thrombosis. *J Thromb Haemost* 2005; 3: 1993-7.

A Potti, A Bild, H Dressman, D Lewis, J Nevins & T Ortel. Gene-expression patterns predict phenotypes of immune-mediated thrombosis. *Blood*. 2006;107:1391-1396



## What is the Best Way to Treat Migraines in Patients with Clotting Disorders?

Written by: **Jacqueline Puga, Pharm. D. Candidate**

**University of Colorado at Denver and Health Sciences Center School of Pharmacy**

Reviewed by: **Al Lodwick, RPh, MA**

Migraines are considered a chronic illness, and occur more commonly in patients with Lupus and/or the Antiphospholipid Syndrome than in the general population. Migraines accompanied with aura are known as classic migraines, while migraines without aura are referred to as common migraines.

Common migraines are the most prevalent type and make up approximately 75% of migraines. Migraines are classified as common when the patient has had an attack that lasts at least 4 to 72 hours. Additionally, two of the following four qualities must be present; pain on one side of the head, pulsing or throbbing pain, pain severe enough to impair or prevent daily activity, or pain that is intensified with exertion. The attack must be accompanied by nausea; vomiting; or sensitivity to light and noise.



An aura is a sensory disturbance that occurs prior to the migraine attack. To be diagnosed as having a classic migraine, patients must have two or more attacks with no less than three of the following symptoms; at least one fully reversible aura, one aura that develops gradually over more than 4 minutes or in succession, no single aura that lasts greater than one hour, and the headache itself must begin before, at the same time, or no more than an hour after the aura.

Once properly diagnosed it is important to discuss treatment options with the doctor. Abortive therapy is used to stop a migraine attack once it has started. Abortive treatment medications include triptans. This class includes the following medications: Imitrex® (sumatriptan), Maxalt® (rizatriptan) Amerge® (naratriptan), Zomig® (zolmitriptan), Relpax® (eletriptan), Axert® (almotriptan), Frova® (frovatriptan). Triptans work on the serotonin receptors in the brain, however, this leads to the constriction of blood vessels, and occasionally a patient may also have blood vessel spasms. This is why triptans should be used with

caution in patients with a history or risk factors for stroke, uncontrolled diabetes, high blood pressure, or heart disease. Patients suffering from the Antiphospholipid Syndrome would fall into this classification. The ergotamines are another effective class of abortive medications, but cause vaso-spasm more commonly than the triptan class and have the same precautions.

Studies have not been published nor are they readily available to the public regarding the frequency of these adverse effects. Studies may not have been done on people with clotting disorders. The warnings regarding the use of these medications are from the Food and Drug Administration (FDA) package inserts and are not a result of any published studies done specifically on this population.

Therefore prevention is vital in patients with the Antiphospholipid Syndrome. It is important to try to identify and modify migraine triggers. Keeping a headache diary may help a patient to identify their triggers. Common triggers include foods; especially those that contain tyramine, phenylethylamine, tannins, sulfites, or monosodium glutamate (MSG). Some examples of these foods are: beers, wines, cheese, seafood products, peas, pickles, olives, sauerkraut, fresh and processed meats, apple juice, coffee, tea, and dried fruits. Other common triggers are abrupt weather changes, low blood sugar, bright or flickering lights, emotional stress, hormone changes, intense physical exertion, and poor sleep habits. It is important to eat a healthy diet, eat frequently, and get regular rest. There is some evidence that 400 milligrams of Vitamin B2 daily can reduce migraine attacks by half. Doctors can prescribe medications to help prevent migraines. Preventive medications can take two to four months to become fully effective. These classes of medications include beta-blockers, anticonvulsants, calcium-channel blockers, antidepressants and non-steroidal anti-inflammatory drugs (NSAIDs). Patients with other medical conditions may choose to try a preventive agent that can be used to treat both the

migraine and other conditions such as high blood pressure, atrial fibrillation, seizure disorders, depression, etc. Beta-blockers with good efficacy data are Inderal® (propranolol) and timolol. Calan® (Verapamil) is the calcium-channel blocker that is most commonly used and most studied. Anticonvulsants that are used are Depakote® (valproate acid, divalproex sodium) and Neurontin® (gabapentin).

If prevention is not enough and an abortive agent is needed, then therapies typically reserved as second-line agents should be considered. Second line abortive agents would include opiates like butorphanol, a nasal spray. Other options include Lidocaine nasal drops, which may provide headache relief for at least an hour, or NSAIDs.

Although triptans and ergotamines are not completely contraindicated in patients with the Antiphospholipid Syndrome, it is important to note that they may increase the patient's risk of heart or circulatory problems and should be used with caution.

### References:

Migraine Headaches. Mercy Medical Center Des Moines. Available at: <http://www.mercydesmoines.org/ADAM/WellConnected/articles/000097.asp>. Accessed October 1, 2007.

For more information on this topic: Courtesy of Mercy Medical Center:

National Headache Foundation, 428 West St. James Place, 2nd Floor, Chicago, IL 60614-2750. Call (888-NHF-5552) or (312-388-6399) or (<http://www.headaches.org>)

American Headache Society (<http://www.ahsnet.org/>) and affiliated organization American Council for Headache Education (<http://www.achenet.org/>)

19 Mantua Road, Mt. Royal, NJ 08061. Call (856-423-0043) AHS Publishes the journal *Headache* (<http://ahsnet.org/journal/>)

MAGNUM (Migraine Awareness Group: A National Understanding for Migraineurs), 113 South Saint Asaph Street, Suite 300, Alexandria, VA 22314. Call (703-739-9384) or (<http://www.migraines.org>)

American Academy of Neurology, 1080 Montreal Avenue, St. Paul, Minnesota 55116. Call (651-695-1940) or (<http://www.aan.com/>)

Web site offers good information and provides names of neurologists for specific locations

National Institute of Neurological Disorders and Stroke, Building 31, Room 8A18, 31 Center Drive, 2540, National Institutes of Health, Bethesda, MD 20892-2540. Call (301-496-5751) or (800-352-9424) or (<http://www.ninds.nih.gov/>)

American Medical Association information site for migraine (<http://www.ama-assn.org/special/migraine/>)

Upstate Medical University (State University of New York) has an excellent migraine Website, designed for doctors, but accessible to the patient, as well. (<http://www.upstate.edu/neurology/haas/hpmir.asp>)



## General Management of the Patient with a Positive Antiphospholipid Antibody Test: What Evidence Is Available For You and Your Physician To Consider?

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

*It is your reality...* you are at your first return visit with your doctor who ordered several laboratory tests of your coagulation (blood clotting) system after assessing your personal history, family history, outside medical records, examination, and you have just been told that “your antiphospholipid antibody syndrome test (s) are positive”. What should you (and your doctor) discuss and consider for your management? In Part 1 of this review, use of aspirin will be discussed.

### Why There Is No One Answer and One Controlled Trial With All the Answers Just For You

While everyone wants “evidence-based medicine”, where large randomized controlled trials (RCTs) of various medications are looked at in similar study patients over time vs. those given a placebo (the control or “no treatment” group), antiphospholipid antibody syndrome (APS) medicine, like a lot of medicine, is not there yet and there have been few RCTs. Even when studies appear well designed and well controlled, and the basis for looking at a treatment comes from eminent doctors and scientists experienced at how aPL antibodies act in the body is considered in the design of the studies, problems in interpreting the final data from studies, and how they apply to the patient in the “real world” arises. Sometimes design glitches occur in studies. Some examples include whether a) the right number of patients was enrolled to detect a treatment effect, “power of the study”; b) the size of the expected difference between treatment and no treatment, “effect size”, or c) the treatment group patients actually took a medication. When an RCT has not been done or did not show the expected benefit of a treatment over placebo, your doctor has to discuss with you “eminence based medicine” or lessons learned from what are considered the “best practices/best doctors”. This often involves lessons learned from blood clot problems in other specialties.

*You are an individual and your particular*

*case may involve some features that separate you from the study patients. What is most likely to have the right balance of “helpful vs. harmful” effects on you is the major concern of your physician to prevent the effects of aPL antibodies in contributing to blood clots and cell or organ damage in you. Let’s look at the major approaches used to manage your positive aPL test.*

### Before Anti-Thrombotic Medications Are Prescribed: Lifestyle Choices to Help Your Blood Clotting System and Cells Be the Best They Can Be.

Because aPLs of any kind (whether identified by the immunologic based tests or the coagulation based tests) can affect the blood clotting factors, the lining cells of the blood vessels (endothelial cells), and the circulating cells called platelets, you as a patient should aim to decrease any personal risk factors you have that in the presence of a positive aPL test adds to the increase risk for blood clots (thrombosis) by maintaining a) a healthy weight, b) daily exercise, c) a normal blood sugar, d) normal blood lipids (the several types of cholesterol that come in both good and bad forms), and e) stopping smoking. Talk with your primary care provider about being sure all these issues are being addressed.

### What Does A Positive aPL Test Mean For the Risk of Thrombosis?

Merely having a positive aPL test does not equal a diagnosis of APS or a diagnosis of SLE. Infections or medications of various types can cause aPLs to appear but they are often low titer (low level) and transient (they are not sustained); about 5% of the normal population will have an aPL at any time (see prior Newsletters and FAQs for more information). The Sydney modification of the Sapporo Criteria for the Clinical and Laboratory Diagnosis of APS now require 2 positive tests 12 weeks apart, up from 6 weeks apart. These criteria were designed to be guidelines for the purpose of identifying similar patients for RCTs and population studies, and are not applicable to the diagnosis of

APS in an individual patient. Persistently positive aPL test are unusual in healthy individuals: <2% of healthy blood donors with a positive aPL maintained that test positivity when retested 9 months later. The presence of positive aPLs ranges from 4% - 21% among patients presenting with thrombosis. So an aPL must always be interpreted in light of a) the

company that it keeps other symptoms that are associated but not diagnostic of APS, such as migraines, livedo reticularis, etc; b) the exposure in the environment that are special situations where increased clotting is a risk on top of having a positive aPL, such as pregnancy, exposure to hormones for birth control or menopause, or c) whether there is additionally a personal or family history of inherited problems with the clotting system, such as Factor V Leiden mutation, tetrahydrofolate reductase (MTHFR deficiency), or protein S and C abnormalities.

A recent systematic review (a survey which compares and assesses the quality of published literature) by Lim et al 2006 looked carefully at MEDLINE and Cochrane electronic databases for relevant RCTs, meta-analyses (data about the data) of RCTs, and prospective cohort (patient group) studies of how the thrombosis risk is treated in patients with aPLs or APS.

From their analyses of published studies from all over the world, they estimated that the absolute risk of developing a new thrombosis is <1% per year in healthy patients with a positive aPL who have not had a history of prior thrombotic events. That rate increases up to 10% per year in women who have had a history of losing babies but no prior thrombosis. For patients who already had a venous thrombosis who discontinued anticoagulant therapies in the prior 6 months, the rate is higher than 10% per year (See Lim et al reference for details).

*(Continued on page 8)*





## My Journey with APS ~ Kristina's Story

Written by: Kristina Waggoner

My story begins over two years ago when I went in search for the cause of many mysterious symptoms that I was experiencing. I had debilitating fatigue, muscle pain and spasms, bone and joint pain, and vision problems to name just a few. I went to specialist after specialist looking for answers. Some doctors genuinely felt there was something wrong, but after extensive testing, couldn't identify the culprit. Most of the doctors just shook their heads at me, stating that I was manifesting physical symptoms from stress and anxiety.

I knew something was terribly wrong with my health. I swore that I would fight whatever was wrong with me. I wasn't going to give into my symptoms, but little by little my symptoms overwhelmed me. I gave up my dream of going to college after only completing one year. I tried to work, but kept coming down with illness after illness. I decided that my dreams could be put on hold. I had faith my doctor would figure out what was wrong with me, and then fix it with some kind of treatment.

My primary care physician was at the end of his rope, too. It was like trying to do a jigsaw puzzle with missing pieces. Then, in February of 2006 the missing pieces began to appear when I had my first pulmonary embolism, a blood clot in the lung. I tested positive for the Lupus Anticoagulant, a type of antibody that is an abnormal part of the immune system. This positive test meant that I have an autoimmune disease called Antiphospholipid Antibody Syndrome, or APS for short. Ten days after being dismissed from the hospital for my first clot, I suffered a massive pulmonary embolism. I had air outside of my lungs so a procedure called a pneumothorax was done to release the air, but then I developed fluid outside the lungs, which required a chest tube to be placed. My right lung collapsed, hemorrhaged, and led to right side heart failure. I was life-flighted to a hospital better equipped to care for me. I was told I later, that death had been very close. Finally, after paying a high price, my doctor and I had the answers we had been searching for. I realized shortly after I came home that over the course of the last year, I had spent over 30 days in the hospital battling various illnesses, all probably related to APS. It has been a little over a year since my first and last clotting event. I have recovered as much as I can physically, and I am grateful to be alive.

You might think that this is the end of my story, but really it is just the beginning. Knowing what

was wrong with me didn't fix the problem, new medication helped, but the illness itself just led to more issues. Going back to school or work was out of the question. My immune system just can't handle the exposure to viruses and bacteria borne illness. I had to seek assistance from Social and Rehabilitation Services (SRS), which put a dent in my pride. I applied for Social Security (I am currently awaiting a decision after several denials). I suddenly knew what it truly meant to be humble, to depend on other people to meet even the most daily needs. I now understand what it means to have to reach for someone else's hand.

My symptoms make it difficult for me to even plan an evening out with family or friends. From day to day, my symptoms change. I may feel pretty normal one day, and the next day may find me battling debilitating fatigue, strange rashes, and pain that I am often unable to tame with my medications. Explaining APS to other people is frustrating, it's not like telling someone you have cancer, something almost everyone can relate to. It is a relatively "new" disease, discovered in the early 1980's, and because of this, there is still much that is unknown about how APS affects the body, and what symptoms are related to it. Navigating care for APS is also difficult since there are few doctors that truly understand what is known of the disease process.

I realized quite suddenly one day that it was as if I were living in suspended animation. I could see life going on all around me, but I didn't feel a part of it. I didn't realize how much we define ourselves by the work we do. Our careers provide us with a title and experiences that most other people can relate to. Explaining why I am not able to work is like walking a tight rope. APS is, for the most part, is an invisible disease. Most of the time, even when I feel awful I look perfectly fine. I have heard many times that "but you don't look sick". Sometimes I reply, "Thank goodness for that, because if I looked as sick as I feel, I would need a paper bag to wear over my head". I also have trouble with telling people when I am not feeling well because it makes me feel guilty about being sick (even though I know it shouldn't), and I have found that most people really don't want the long answer about how I feel anyway.

So, here we are at the beginning. "Beginning of what?" you might ask. The first of many beginnings of trying to learn to live with a chronic, life-threatening illness. Death held me close once, and let me go. The next time, he might decide he likes me so much to take me

home. "Live like you are dying" is the motto of many people. It's much different when it becomes your reality, when you know it could come at any time. There is much to prepare for, and there will never be enough time. At the age of 32, I have to prepare for my death, whether it comes or not. There are arrangements to make for a will, so my nine year old son will be cared for if I pass on, as I am his sole parent. I have to consider a DNR order (Do Not Resuscitate) in the event I become unable to make decisions regarding my health. These decisions are like weights on my shoulder. I know how important it is, but have not been able to bring myself to deal with it because I simply don't want to think about it.

I am coping with learning how to be contributing member of a society that APS has excused me from. I want things that I can no longer accomplish, and I have to find new goals that I am capable of attaining. We have all seen the people on TV that are battling disease and how admired they are because they never complain and are always positive. I always thought, if I get sick, I am going to be that person. I am going to stay positive and I am going to fight everyday. I am going to go to work/school and nothing will stop me. My, how things are different when you are suddenly on the inside looking out! I admire people with that determination and motivation. I wish I could be that person, but it is simply not me. Some days, I want to kick, scream, and rage. Some days I lose my faith and curse God. Life is short, but some days I can hardly get up off my knees to meet the day, and I can't find the blessing in the storm. I am acutely aware of the beauties of life and the world we live in on a daily basis. Almost dying will open your eyes to many things people take for granted. The problem is that some days, those beauties are just beyond my reach compared to the immediate physical feelings I am dealing with.

You might ask what I have learned so far in this journey after a year has passed. Well, I have learned that it is alright for me to feel the way I do; it is ok for me to grieve, to be angry, to be faithless, and to be sad. It is alright to ask for a hand up when I am unable to pull myself out of an abyss. That recognizing and grasping the gift of life isn't always simple as it may seem. Most importantly I am learning that I can endure, and that I can hold on long enough to yesterday's sunshine to get through the storm of today. I now know that there will be no magic wand, miracle drug, or even a cure for me and others with APS today, but for every tomorrow that I am granted, I can dream of the possibility.



# Different Ways To Donate To The APSFA This Coming Holiday Season

Written by: Heidi Ponagai



The 2007 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.

## Donation Ideas

There are many 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 APS informational booklets, burgundy ribbon lapel pins, postcards, and APSFA pens for sale. All profits of these sales go to the foundation.
- ◆ We have our ongoing PhoneRaiser fundraiser that allows you to donate used cell phones and some ink cartridges and the APSFA gets the profits. This has been a great success, and in 2007 so far we've raised \$1250.00 with this fundraiser alone!
- ◆ 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 all of 2007. We do have most of 2008 open, so act now if you'd like to sponsor a certain month!



- ◆ We also have continuous 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](http://www.apsfa.org/donate.htm)

Please be sure to have all donations for 2007 post dated by 12/31/07.

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

## APSFA Online Giving Tree

Our "Giving Tree" was a great success last year, so we're bringing it back this year! Our tree will be "planted" by the time this newsletter goes to print, so please see our website for more details and help us decorate our tree!

The "Giving Tree" will work just like last year, with each ornament on and package under the tree representing a donation. All "Giving Tree" donations are tax deductible.

There will be buttons for making special "Giving Tree" ornament donations on the site. Ornaments will come in different shapes and colors to represent different donation denominations, and just like last year, donor names will be

printed underneath the tree.

Ornaments can also be in memory or in honor of someone and this year they will have a little different look to them so they stand out from the rest of the decorations.

We'd like this year's "Giving Tree" to be even a bigger success than last year's so please consider helping us to decorate our tree.

Information about our "Giving Tree" can be found on our website at:

<http://www.apsfa.org/givingtree.htm>



## The APSFA CafePress Online Store

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

With every item purchased, the APSFA receives a small donation. We have made over \$600.00 so far in 2007 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 \$7.99 each and are made of porcelain.

Check out our store online at [www.cafepress.com/apsfoundation](http://www.cafepress.com/apsfoundation) to buy APS gear and help the APSFA at the same time!



(Continued from page 5)

The literature tends to support that when followed up, some patient groups are more likely to experience thrombosis with a positive aPL than others, as a general guideline. There are no perfectly predictive lab tests at this time.

### The Initial Medication Used To Prevent Thrombosis in Patients with Positive aPLs: Aspirin, What Do We Know Now?

Aspirin blocks enzymes that act to make platelets stick together, which is the first event leading to a blood clot, and also acts to counteract aPL-induced endothelial cell activation, and in pregnancy, stimulates interleukins which help placental components grow. Aspirin has long been used as first-level or initial prevention in blood clots in the heart and brain. The Physicians' Health Study did not find that higher dose aspirin (325mg a day) prevented strokes and heart attacks in older male physicians after long follow-up, but that study was not designed to answer the questions for APS patients with and without SLE, who are by their very nature often younger females. The Womens' Health Study showed that low dose aspirin (LDA) reduced the rate of first brain clot (stroke) by 17% versus no LDA, but again, that study was not designed to follow patients with autoimmune disease, who are different.

A consensus report published in 2003 representing literature review and experience of eminent aPL physician-investigators (what would be termed "eminence based medicine") concluded that for patients who are not pregnant the use of LDA, 81 mg a day was recommended. (Note to readers: the evidence for and separate use of LDA as a component of treating aPL+ pregnancies will not be addressed in this review).

Aspirin is safe if the patient has no real risk of having a severe stomach ulcer or a tendency to GI bleeding, or aspirin allergy or sensitivity, which can be associated with nasal polyps and sensi-

tivity to yellow dyes. As with all medications, you and your healthcare provider need to consider the "risk-to-benefit" ratio. Petri and other eminent investigators have also stated in their review articles and their own patient cohorts with >18 years of study the belief that LDA is the first medication to use for many patients with a positive aPL; there are others who list in their Tables that "no treatment is needed" but in the details in footnotes state that "LDA or hydroxychloroquine can be used".

The final results of the first RCT designed to assess the efficacy of LDA in aPL+ patients, and patients with APS with and without SLE, were recently published by Erkan and Lockshin. The study, called APLASA (Antiphospholipid Antibody Acetylsalicylic Acid) was a multicenter, randomized, double-blind, placebo-controlled clinical trial where persistently aPL-positive individuals (who had no blood clots yet) were randomized to receive LDA or placebo. In a separate observational and parallel study, persistently aPL-positive individuals already on aspirin or who declined randomization (where they had a chance of being given the placebo) were followed up prospectively.

In the APLASA study, 98 individuals were randomized to receive aspirin or placebo over a mean +/- standard deviation of 2.30 +/-0.95 years: 48 got LDA and 50 placebo. In the observational study, 74 nonrandomized individuals were followed for the same time as the APLASA study: 61 received LDA and 13 did not. In the APLASA study, the acute thrombosis incidence rates were 2.75 per 100 patient-years for LDA-treated subjects and 0 per 100 patient-years for the placebo subjects, and the p value was not significant. Similarly, in the observational study, the acute thrombosis incidence rates were 2.70 per 100 patient-years for aspirin-treated subjects and 0 per 100 patient-years for those not treated with aspirin. All patients in either study except 1 had other thrombosis risk factors and/or systemic autoimmune disease at the time of thrombosis.

This RCT did not show that asymptomatic persistently aPL-positive individuals benefitted from LDA in preventing thrombosis. The overall rate per year of developing a clot was low and the importance of other factors contributing to thrombosis was emphasized. No one had serious adverse effects from LDA.

However, as noted by the Authors themselves, some of the difficulties cited above regarding power, the multiplicity of factors contributing to thrombosis in aPL+ patients with autoimmune disease, our primary focus, the estimation of the effect size, the trends for aPL antibodies during the study, are part of this RCT. Additionally, no independent ascertainment of actual LDA use or estimate of whether the LDA actually affected the platelets was built into this study. Some patients have aspirin resistance, which could also have affected the results.

On the other side, using computer modeling looking at the use of LDA to prevent thrombosis in APS patients, Wahl et al in 2000 showed that there was a benefit in using LDA to prevent thromboses in aPL+ patients, especially for those with SLE and APS.

However, if the caveats I mentioned above are met regarding no major risks of bleeding or aspirin allergy, I continue to use and recommend LDA as a first therapy in patients with aPL positivity. In Part II I will try to extend those recommendations regarding the roles of hydroxychloroquine and warfarin therapies.

#### References:

- Lim W et al: Management of APS. JAMA 295: 1050-57, '06.
- Erkan D et al: ASA for Primary Thrombosis Prevention in the APS: Arthritis & Rheum 56: 2382-91, 2007
- Erkan D, Lockshin M: New Treatments for APS. Rheum Clin N Am 32: 129-48, 2006
- Petri M: Clinical and Management Aspects of APS. In Hahn BH, Wallace DJ: Dubois' Lupus Erythematosus, Ch 65, p 1262-97, Lippincott Williams Wilkins, 2007
- Wahl DG et al. Prophylactic antithrombotic therapy for patients with SLE with or without aPL: do the benefits outweigh the risks? A decision analysis. Arch Intern Med 160: 2042-8 2000.





## Remembering Precious Babies

Written by: Madonna Daley, MS, RN Bereavement Educator

*“At the going down of the sun and in the morning we shall remember them.”*

~ Laurence Binyon

These words may reflect how you are feeling since the loss of your baby during your pregnancy. You can't help but think of your baby and what might have been. You imagined bringing your baby home, celebrating birthdays, playing with cousins, or the first day of school. Sadly, your dreams for your baby will not come true.

### Mending a Broken Heart

With the loss of your baby and the hopes and dreams you had, grief may feel like a constant, heavy companion. Often when we are in the midst of our grief we wonder, “Is it normal to feel this way?” It may be comforting to know there are common feelings among parents who have experienced a loss. Initially numbness and shock are present, and the reality of the loss might be too hard to accept. Then other feelings start to surface. You might experience anger or guilt, not sleeping or eating well, or finding yourself thinking about the baby constantly. Time passes and you are still grieving. You may feel depressed, tired, and not able to meet the demands of everyday life. All of these manifestations of grief are the natural way of adjusting to what has happened and part of the process to heal a broken heart. Grief has been described as the toughest job you will ever have. Eventually you will find yourself starting to feel “normal.” There will be times during the day when you don't think about your baby, or when you realize you enjoyed an activity that brought you pleasure before the loss. It could take 18 to 24 months,

or longer, before you feel your life is put back together.

### Grieving Differently

At a time when spouses or partners need each other, it may feel as if there are miles between you. Each of you may behave differently after the loss. One may be quiet, withdrawn, or going on with everyday life acting as if nothing happened. The other may cry all the time, wanting to frequently talk about the baby, or have the need for their partner to feel the same way as they do. Fathers could have the tendency to want to “do something” to express their grief instead of talking about the loss. Mothers might feel like they “do not want to see anyone, go anywhere, or do anything” while they are grieving. It's important to recognize that everyone, even those who have been married or together for a period of time, grieve differently and in their own way. One way of grieving is not better than the other; it is just your way. An approach to understand each other's individual way of grieving is to talk about it. Communication between parents during this time of grief can lead to a deeper relationship, whereas not talking might lead to misunderstandings. Create the opportunities for these conversations to occur.

### On Being a Parent

You might be wondering if you are still a parent because your baby died before it was born. The answer is “yes.” You may not have had the chance to know your child,



but he or she is still real in your life. Other families who have lost a baby during pregnancy have said being acknowledged as a parent was very important to them. There are special ways in which you can parent your baby. Examples would be naming your baby, holding a special ritual honoring the child, writing a letter to the baby, planting a tree or flower in memory of the infant, or donating money to a special fund in memory of the baby. Explore what would feel right for you to honor your baby and acknowledge yourself as a parent.

### Resources

Resources regarding grief and loss of a baby are available and may be helpful to you. Bereavement and Advance Care Planning Services has pamphlets discussing miscarriage, father's grief, grandparents' grief, talking with children, family and friends, and many other topics. You can find them in the online catalog at [www.bereavementseervices.org](http://www.bereavementseervices.org). Other organizations, such as Share Pregnancy and Infant Loss Support and Mothers in Sympathy and Support, also offer online resources as well as parent-to-parent support. In addition, your community might offer other sources of support such as a parent support group. Call 2-1-1 to learn about your local resources.

Parents say they will never forget the child they lost; the baby will be in their hearts forever. May you find inner strength from the memories of your baby.

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Bereavement and Advance Care Planning Services is a department of Gunderson Lutheran Medical Foundation, Inc.

## From the APSFA FAQ Page:

### If my antibodies become negative, should my doctor stop my anticoagulants?

Not necessarily. Sudden stopping of an anticoagulant could, under some circumstances, have extremely disastrous results. And as I have often cautioned medical students: While laboratory assays are invaluable both in diagnosis and in following treatment, the physician should treat the patient, not the lab test.

How to handle this situation is very much a clinical decision, based not only on blood values but on the doctor's experience, familiarity with the patient's history, examination and, to be frank, gut feelings (medicine is an art as well as a science).



It should be noted, too, that in such a situation, the physician may feel that further lab tests should be ordered, since there are additional proteins (unrelated to APS) involved in the clotting process. Assessing the levels of these elements may be helpful in clarifying the picture.

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**APS Foundation of America, Inc.**

**Our Mission Statement**

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

Sponsored by: 



This time of year is a perfect time to send fresh flowers to your 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](http://apsfa.flowerpetal.com) and help us make a difference.

