ANTIPHOSPHO...WHAT?

APS Foundation of America, Inc. Newsletter

Volume 15 Fall/Winter 2009

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

A Joyous Holiday Season!

Influenza Vaccination in Patients with Antiphospholipid Antibodies

Written by: Thomas L. Ortel, MD, PhD

Influenza, more commonly known as the flu, is a highly contagious acute respiratory disease. Symptoms include high fever, chills, headache, myalgias (muscle aches), dry cough and fatigue. Infection of the respiratory tract may lead to bacterial infections that can result in severe pulmonary complications, including death from pneumonia. Influenza is caused by an RNA virus of which there are three types (genera): A, B, and C. Type A viruses are the most important type clinically, and the 2009 pandemic* influenza virus (H1N1), commonly referred to as 'swine flu', is a Type A virus.

Vaccines for influenza are developed each year to prevent vaccinated individuals from becoming infected with the influenza virus. The vaccines are based on worldwide surveillance data and reflect the most likely strains that will be problematic in the year to come. The usual seasonal vaccine is actually a 'trivalent' vaccine, containing two different influenza A-type viruses and one influenza B-type virus. This year's seasonal vaccine is not protective against the pandemic H1N1 virus, however, which is why there is a second, 'monovalent' vaccine that is available as well.

Patients with autoimmune rheumatic diseases, such as rheumatoid arthritis, lupus, and antiphospholipid syndrome (APS), have a higher risk for developing complications related to the flu, including pneumonia. Patients with autoimmune rheumatic disorders also frequently take medications that may weaken the immune system, including steroids (for example, prednisone, dexamethasone), methotrexate, hydroxychloroquine (Plaquenil), azathioprine (Imuran), and rituximab (Rituxan), among others. In contrast, anticoagulant medicines taken for the treatment of thromboembolic events, such as low-molecular weight heparin (e.g., enoxaparin, or Lovenox) or warfarin (Coumadin), do not affect the immune system.

The influenza vaccine is highly efficacious in the general population. Even if the "match" between the virus used in preparing the vaccine and the virus causing flu is relatively poor, the vaccine is about 60% effective and decreases the risk for death (Medical Letter, 2009). In contrast, several studies have suggested that the immune response of patients with lupus to influenza vaccine may be decreased compared to the general population (Holvast, 2007). Other studies have suggested a normal response to influenza vaccine in patients with lupus, however. In addition, the use of immunosuppressive medicines, such as those listed above, may decrease the immune response of the patient. Most of

(Continued on page 4)

Are You Mapped?

Do you have a pin in our map?? If not, please add it. We are watching in amazement to see the clusters of APS people forming. Our Frappr map is located at: www.frappr.com/apsfa

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!

Inside this issue:

Letter from the President

Where has 2009 gone? We are already coming upon the bustling Holiday Season.

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.

We have gotten much needed press in the past few months. The first big thing was APS was a diagnosis on House, MD. You can view the full episode on FOX.com. The show title was "Karma". The second event was a more somber awakening on how sneaky this disease is with the death of Tom Sparks. Tom died from APS suddenly and somehow the Associated Press picked up on the story. It brought a lot of attention to APS and the APSFA. Our deep condolences go out to the Sparks' Family.

We are Bronze Donors for the 13th International Congress on Antiphospholipid Antibodies. This conference will be held in Galveston, TX but due to very limited funds & being that we are all APS patients or caregivers of APS patients we will not be able to physically attend unless our situations change dramatically.

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

Special thanks to Candy Czernicki for proof reading the articles.

Different Ways To Donate To The APSFA This Coming Holiday Season

Written by: Heidi Ponagai

The 2009 Holiday season is right around the corner and is sneaking up on us faster than you think! It is the perfect time to start thinking about where your holiday charity donations are going this year. This page is 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 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.
- On our shopping page, we have links to amazon as well as GoodSearch shopping. When you use these sites to do your online shopping, the APSFA gets a small percentage of the sales!

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 2009 post dated by 12/31/09.

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, names (first initial, last name) 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.

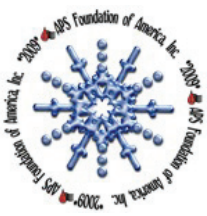
Information about our "Giving Tree" can be found on our website at:

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

The APSFA CafePress Online Store

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

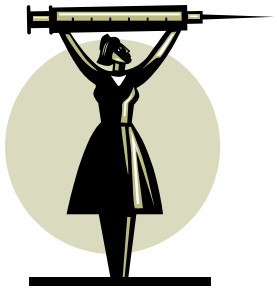
With every item purchased, the APSFA receives a small donation. We have made over $500.00 so far in 2009 just with CafePress sales!! Thank you to everyone who's purchased our items!



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.

This year is the 4th year for our annual exclusive APSFA Keepsake ornament. We 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 to buy APS gear and help the APSFA at the same time!



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the studies investigating the efficacy of the vaccine in patients with lupus have been relatively small.

Adverse reactions to the inactivated influenza vaccine (administered by a shot) are uncommon in the general population. In general, the influenza vaccine also appears to be safe in patients with lupus and similar autoimmune disorders. In one controlled study of patients with lupus who received the influenza vaccine, there was no significant increase in disease activity using the SLE disease activity index (SLEDAI) (Abu-Shakra, 2000). Influenza vaccination in patients with lupus has been associated with the generation of autoantibodies, including anti-Sm, anti-RNP, anti-Ro, and anticardiolipin antibodies, but this effect has generally been short term and not associated with clinical events (Abu-Shakra, 2000).

Tarjan and colleagues (2006) looked specifically at antiphospholipid antibodies in 18 patients with lupus who were receiving a third annual influenza vaccination (in other words, the third year that they were receiving the vaccination). They excluded patients with an active lupus flare, and measured anticardiolipin and anti-$\beta_2$glycoprotein I antibody levels on the day of vaccination, and at 4 and 8 weeks after vaccination. They showed that influenza vaccination was associated with significantly decreased anticardiolipin IgG antibody levels after vaccination, but anti-$\beta_2$glycoprotein I antibody levels, on the other hand, significantly increased (Tarjan, 2006). None of the patients in this small study developed thrombotic complications, however.

The Centers for Disease Control and Prevention have recommended that persons with weakened immune systems, including people with inflammatory arthritis and APS, should get both the seasonal flu shot and the new pandemic H1N1 flu shot (www.cdc.gov/h1n1flu/arthritis.htm). One difference between the two influenza vaccines is that persons over 65 years of age, including those with inflammatory arthritis, are not in the highest priority group for the pandemic H1N1 virus, since the risk for this group appears to be less than the risk for younger age groups. They are in the next risk level, however, and should inquire about the availability of the vaccine. All patients with APS should first review with their healthcare provider concerning their individual risk for the flu and the role for vaccination. The nasal-spray flu vaccine, which uses a live-attenuated influenza virus, is not approved for use in patients with autoimmune rheumatic diseases.

**A 'pandemic' refers to an infectious disease that is epidemic across a broad geographic area, for example, several continents, or even the whole world.*

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The 13th International Congress on Antiphospholipid Antibodies (APLA 2010)

Written by: Silvia Pierangeli

The 13th International Congress on Antiphospholipid Antibodies is a triennial meeting to showcase the latest developments and achievements in science and clinical care with regards to Antiphospholipid Syndrome (APS). APLA 2010 will be the primary forum for worldwide interaction between leading researchers, physicians and other health professionals with interest in APS.

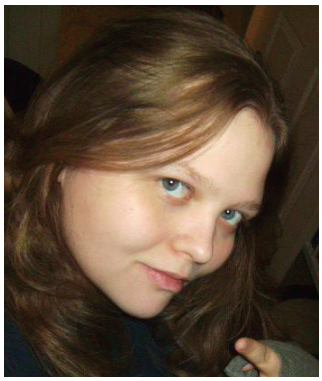
The congress will include state-of-the-art lectures, selected abstract oral presentations, poster sessions, a pre-conference consensus workshop to re-evaluate and validate the Sapporo revised classification criteria and discuss un-solved issues such as treatment and diagnostics in APS. In addition, APLA 2010 will include pre-conference wet workshops where participants will be able to evaluate "hands-on" new tests proposed to help in the confirmation of diagnosis of APS and discuss with experts issues on standardization of currently used assays. APLA 2010 will include for the first time "Meet the Professor" sessions on topics such as: "Treatment", "Diagnosis" and "Equivocal Cases of APS." For patients there will be a superb program focusing on the latest developments on all aspects of APS including new treatments and clinical trials. We are confident that attendees and participants will get the most updated scientific evidence on APS at APLA 2010.

**The APSFA have been invited to attend this event. We are planning to do everything we can to attend, however, because we are APS patients ourselves, we may not have the health to do so. We are urging people to attend the patient portions of the event if you are able to.*

Tara's APS Story

Written by: Tara Jensen

I remember the pain that shot through my chest, no my lungs, I knew it was my lungs from the moment it had started, and I remembered the nurses and doctors at Blessing Hospital rolling their eyes and quickly dismissing me when I tried to explain the pain. It was a squeezing, stabbing, dull, shape, hot, pounding, heavy pain that ached with each breathe inhaled and exhaled. It hurt from the inside out and the outside in. The doctors insisted I was getting all the oxygen I needed though it felt like I couldn't breathe, that a truck was parked on my chest. I was sent home and the pain only worsened overnight. I begged my parents to take me to Hannibal Regional instead. Once we arrived there everything was a rushed blur for blood work, x-rays and even a CT scan. While I was rushed from the ER to ICU I was pumped full of blood thinners and fitted with oxygen.



I remember when the doctors tried to explain to me what they thought had happened but they seemed to be at a disagreement. Some believed my chest pain was caused by blood clots but others thought it wasn't clear. After having a specialist check my scans they decided to rerun them but by the time they did my second CT scan and round of x-rays whatever the problem was had cleared up. Instead they labeled me with pneumonia and pleurisy. I guess I will never know for sure if I did in fact have the blood clots. I am sure that the blood thinners may have done their job before they decided for sure what my diagnosis was.

All I know was that for those 5 days I was weak and I remember my friends coming to visit me. They were quiet as if they were scared that it was goodbye but that they couldn't say it. I couldn't imagine what I must have looked liked in their eyes to scare them so much but more than anything I remember how scared I was, how alone I felt. I was so weak and helpless and at times when the pain was the worst I thought I was going to die. But most of all I was so confused: If it was blood clots, how did I get them? 15-year-olds don't get blood clots. The doctors told me it was from my birth control but I rarely took my pills (never remembered to take them) and besides that I hadn't been on anything for months.

It was only four years until I found the answer, though. After complaining about leg pain in my calves my doctor insisted on getting some blood work done and an ultrasound on my legs. When the blood tests came back I was told I had Antiphospholipid Antibody Syndrome. My very own doctor didn't know what it was—seriously, he left the room and looked it up. I was horrified! I made him write it down for me on a piece of paper so I could do my own research. To this day I still carry that piece of paper with me everywhere. Soon after I also discovered my mom's brother and their mother had APS as well and with my first visit to my oncologist, which sounded scary all in itself, but between her and my OB (since I became pregnant with Robbie 2 months later) the pieces began to fall into place. I discovered that I had had 3 (at the time, 5 now) early miscarriages and many of my other recurrent medical problems had a reason such as my daily migraines. I have been lucky with my APS; I have only had to be on blood thinners once, which was during my pregnancy with Robbie. Otherwise I only have to take a baby aspirin a day. I do have eye problems--sometimes out of nowhere everything will be blurred or fogged over. I can't make out words or see the lines in the road while driving. One time it happened so suddenly I almost crashed the car.

Most recently I have had memory problems. I would write down appointments and have reminder cards sent in the mail and even call the morning of to double-check the time but still forget about the appointment. I would forget what I was doing or where I was going. I couldn't find even the simplest words like *the*. I couldn't concentrate or comprehend things I was reading or writing. My doctor feared a stroke.

A STROKE!!?! I am only 21!!

Thankfully my scans were clear and I began taking my daily aspirin again (bad memory always forgetting my meds) and my problems seemed to lessen.

It's scary not knowing what this blood disorder can truly do to my body and at times it's annoying to have to check with my blood doctor first about every headache or cramped muscle before seeing my primary care doctor but that is how it is. It's even scary sometimes when I bruise so easily--always have, even when I was a baby, but it's also just a part of my APS; it's a part of my life. Again, though, I am lucky to not suffer as bad as others do with this disorder but it still is important to me. APS is out there but not many people know about it. Sometimes it even gets misdiagnosed. APS is dangerous and if you have it you need to take it seriously.

For Easing Pain Around the Holidays

Submitted by: Tina Pohlman

It's supposed to be the "most wonderful time of the year", but the rush of the holiday season can leave many people anxiety-ridden. Juggling competing demands, such as work, visiting relatives, parties, cook and crowded stores and shopping, can be stressful. And stress aggravates many chronic pain conditions and can trigger pain flare ups. It's important to pace yourself and take plenty of deep breaths.

Here are some helpful tips to reduce stress and help ease pain around the holidays:

Get organized and plan ahead! Make to-do lists and delegate tasks to trusted family and friends, so you won't feel overwhelmed.

Don't feel pressured to entertain house guests. Tell them to make themselves at home and how them where to find the essentials (e.g., towels, newspapers, beverages and snacks). Surround yourself by people who are supportive of you and will pitch in and help.

Be true to yourself. As hard as it might be, put your own needs first. If you feel the need to withdraw to another room to rest, do so. Pass on activities that you're only doing out of obligation; instead, concentrate on those that have meaning to you. You'll be able to enjoy the festivities much more as a result.

Prepare food well in advance or, better yet, consider hosting a pot-luck dinner. Order a pie instead of backing it yourself. If you decide you want to chop vegetable or peel potatoes, do it sitting down rather than crouched over the counter.

Stay on top of your treatment, and plan ahead to avoid interruptions in routine care. Don't let your treatment slip over the holidays. Talk with your healthcare providers to find out who you should call over the holidays, so you can get help when you need it. Be sure to have enough medications on hand as many pharmacies are either closed or have limited hours.

Set expectations. It's difficult to enjoy time with family and friends when you have too many responsibilities and not enough time. Talk openly with loved ones about what activities you think you may or may not be able to handle.

Pay attention to your mood. The holidays have a way of reminding us of loss and how things could have been. If you have the holiday blues, talking about your feelings with friends and family may help.

Keep up with regular sleep schedules, eat healthful meals, exercise within your limits and stay hydrated. If you don't already, consider practicing relaxation techniques, including deep breathing and visualization, to help ease stress.

Avoid crowed stores. Standing in long lines and fighting against masses of people may worsen your pain. This about ordering online or through catalogs instead.

Keep a healthy sense of humor. Remember that not everything has to be perfect.

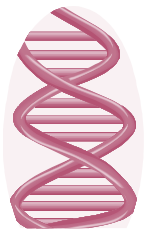
Source: American Pain Foundation

Genetics of Antiphospholipid Syndrome: Update

Written by: Thomas L. Ortel, MD, PhD
Duke University Medical Center

Thank you very much to all the patients and their family members who have agreed to participate in this very important study! Our research program is currently recruiting patients with antiphospholipid antibody syndrome (APS) and their family members to participate in a study investigating this genetic disorder (clinicaltrials.gov # NCT00482794). Currently we have enrolled slightly more than 160 individual patients, and we are working with another 75 patients or so, who are at various stages in the process of completing consent forms and initial paperwork. We also have enrolled more than 120 family members.

We will have a poster at the Annual Meeting of the American Society of Hematology in New Orleans next month, summarizing the preliminary analysis of the first 62 families for whom we have detailed information on both the patient and one or more family members. Most of the probands from these families are female (52 of 62; 84%), and most of these individuals have primary APS (in other words, do not have lupus or an alternative rheumatologic condition associated with APS; 43 of 62, 69%). All of the families have one or more family members with either APS (13 families) or an alternative autoimmune disorder, such as lupus or rheumatoid arthritis (49 families). Eight of the families with family members affected with APS also had one or more other family members with an alternative autoimmune disorder.

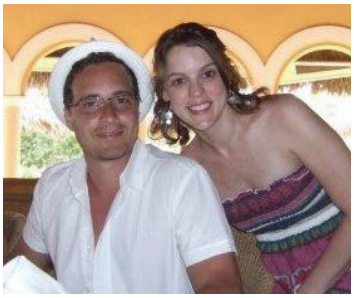


The study is still open and we are interested in recruiting more patients and available family

I Am a CAPS Survivor

Written by: Patrizia Battaglia

Nine years ago, when I was 21, I was diagnosed with Deep Vein Thrombosis (DVT) in my legs, left arm, and pulmonary emboli (PE) in both lungs from taking the Birth Control Pill for 3 weeks. I began Warfarin therapy to prevent future clots, and was diagnosed with Antiphospholipid Syndrome, Factor V Leiden, and Lupus Anticoagulant. The clots reabsorbed and I was back to my normal self within 2 months. When I was 28, my husband and I planned a pregnancy with our doctor at a high risk clinic known for helping pregnant women with blood disorders. I began daily Heparin injections and baby aspirin to prevent clots. Everything went well for the first while, though I battled terrible morning sickness.



At 19 weeks, I developed severe neck and back pain. I found myself in the hospital for an emergency ultrasound to check for clots. For days I suffered from severe pain that no amount of Morphine or Codeine could soothe. I knew something was terribly wrong when I began vomiting bile. I quickly went into respiratory distress and was rushed to another hospital better-equipped to handle my symptoms.

In the ICU, the team of doctors and nurses quickly realized that I had Catastrophic Antiphospholipid Syndrome (CAPS), a rare and fatal complication of pregnancy and APS. I was instantly pumped with 100mg of Cortisone, a steroid used to suppress the immune system and the production of antibodies that were killing me. I endured 10 sessions of Plasma Exchange, a machine that cleans out the bad antibodies that are attacking you, and replaces new plasma into your system through a catheter inserted in your neck. The sessions were long, and I could not move an inch for hours. My husband and close family stood by me every minute of my hospital stay.

I soon contracted "C. Difficile," a bacterium that upsets the normal balance of healthy bacteria in the digestive system, causing diarrhea. Antibiotics combated that problem. As time marched on, things seemed to be getting better, but only for a short while.

My blood pressure soon skyrocketed and I began seeing black spots accompanied by the worst headache I had ever experienced. Little did I know I had Pre-Eclampsia and my unborn baby and I were in grave danger. My blood pressure clocked-in at 200 over nearly 100, and an ultrasound showed that the placenta had spontaneously abrupted, and our baby was no longer with us.

I was induced and delivered a baby girl within 8 hours after a painful labor with no medication other than the Magnesium that was lowering my high blood pressure. My husband and I said goodbye to our sweet baby girl and continued on the path to recovery. The days following the delivery worsened, as my uterus hemorrhaged and I required several blood transfusions. The doctors performed a D&C and an embolization of the uterine artery to block blood supply to the uterus, and stop the bleeding. But the bleeding continued and I was left with a final alternative: a hysterectomy. Luckily the doctors found a window of time when the surgery could be performed despite having thinned blood from the Heparin. I was ordered to strict bed rest, and soon realized that my leg muscles completely atrophied and I could no longer stand up, let alone walk. The Cortisone caused a 90 pound weight gain from my original 110 pound body, and left me with unsightly stretch marks on my stomach and all the way down my inner legs. I felt like a 28 year-old sitting hot-air balloon in a 90 year-old body.

I was finally discharged and sent to a rehabilitation centre where I began intense physiotherapy to regain strength. I learned to walk again with the aid of a wheelchair and a cane, and 4 months of therapy. In retrospect, I recovered quickly, thanks to the healthy lifestyle I had led before my illness.

After much testing, I have never been diagnosed with Lupus, since I do not have the physical symptoms consistent with the disease. I am taking Warfarin drug therapy for life to prevent potential future clots.

Two years have passed, and although I cannot bear children of my own, my husband and I are expecting twin girls via a surrogate mother and an egg donor (since I cannot take the hormones required to stimulate my ovaries for egg production). We are thrilled about surrogacy and we are anxious for their arrival early in the New Year!

Do You Need to Stop Warfarin for Every Procedure?

Written by: Myhao Pham, Pharm D. Candidates
University of Colorado School of Pharmacy
Reviewed by: Al Lodwick, RPh, MA

The American College of Chest Physicians (ACCP) classifies patients with APS as being high risk for developing blood clots in the arteries or veins both before and after surgery.[1] Patients with APS are considered high risk because the syndrome causes the body to have a tendency to form clots even while on warfarin therapy. The procedure itself can cause a sudden worsening of the syndrome marked by clots in multiple organs over a short period of time. The impact of these events is magnified when temporarily stopping warfarin for surgical or invasive procedures. Continuing warfarin lowers the risk of recurrent clots in APS. Choosing to maintain patients on warfarin can place them at risk for bleeding complications [2] According to the ACCP guidelines, the need to prevent an event such as a stroke will favor continuing warfarin if the bleeding risk is low. The potential consequences of clotting events may be fatal or cause permanent disability which outweighs potential bleeding consequences.[1]

Stopping warfarin is generally required to minimize the risk of bleeding in patients undergoing major surgery but minor surgeries or procedures may not require the same precaution.[1] Gastrointestinal, gynecologic, thoracic, urologic, and orthopedic surgeries have a high risk for clotting complications. The risk of developing a clot in the calf is 40-80% for these surgeries compared to 2% for uncomplicated minor surgeries.[2] Studies show that minor surgeries such as soft tissue surgeries do not require stopping warfarin based on risk versus benefits.[3]

Low dose unfractionated heparin (UFH) or low molecular weight heparin (LMWH) are effective in reducing clots when used as a temporary alternative to warfarin, which is also known as "bridging." For patients undergoing neurosurgery, clot prevention is best achieved with a combination of elastic stockings and LMWH.[2] The ACCP guidelines recommend the use of LMWH in the outpatient setting over administration of UFH in the inpatient setting based on cost.[1] Another advantage with LMWH is that it does not require monitoring except in patients with kidney failure.[2] There is an option to use either low-dose or therapeutic-dose of LMWH or UFH. Low-dose LMWH or UFH may have a lower risk for bleeding complications but can be less effective in preventing arterial thromboembolism.[1]

Timing of bridging is important in APS because the goal is to keep periods without warfarin therapy for clot prevention to a minimum. Patients who are already on long-term warfarin may resume therapy on the night of the surgery in many cases. Short-term use of heparin is continued until the INR is within goal range again. Orthopedic surgery allows starting either drug 12 to 24 hours after surgery to balance both clotting and bleeding concerns. [2]

Currently, indefinite life-long warfarin therapy is the recommended standard of care for patients with APS as long as the risk of bleeding does not outweigh the benefits of treatment. [4] Temporarily discontinuing warfarin may be necessary especially in major surgeries or procedures that are associated with a high bleeding risk. Bridging then becomes a crucial method to prevent blood clots with the options being UFH or LMWH.

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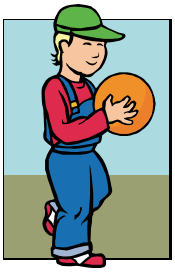
members. We have expanded the enrollment criteria to include all patients with APS who have available family members, preferably parents, who would agree to participate in the study. It is not a requirement that one or more family members need to have APS or an alternative autoimmune disorder; they just need to agree to participate! We will still screen the family members for antiphospholipid antibodies, to see if there might be asymptomatic individuals with these antibodies. Interested individuals may contact me (thomas.ortel@duke.edu) or our clinical research coordinator Letitia Talbott (letitia.talbott@duke.edu) for more information about participating in this study.

Stroke in Children ~ It's Not the Same As in Adults

Submitted by: Tina Pohlman

Stroke in children is not as rare as once thought, and the symptoms do not mirror stroke in adults. In its first scientific statement on the topic, the American Heart Association / American Stroke Association addresses treatment, symptoms and risk for stroke in infants and children.



"Children and adolescents with stroke have remarkable differences in presentation compared with adults," said E. Steve Roach, MD chair of the statement writing group and professor of pediatric neurology at the Ohio State University School of Medicine. "In newborns, the first symptoms of stroke are often seizures that involve only one arm or one leg. That symptoms is so common that stroke is thought to account for about 10% in full-term newborns. Seizure is a much less common stroke symptom in adults."

A major treatment difference between adult and child stroke is the use of tPA. The clot-busting agent is the cornerstone of treating adult ischemic stroke but, in the new statement it's not generally recommended for treating young children, especially newborns.

"Stroke in children in uncommon but not as rare as we used to think," said Roach. "Even as recently as 20 years ago, stroke was an unlikely diagnosis in a child because it was strongly associated with adults with atherosclerosis.

The risk of stroke from birth though age 18 is 10.7 per 100,000 children per year. The risk of stroke in children is greatest in the first year of life, particularly in the first two months. It decreases after that. Data from the statement shows that stroke in the first month of life (neonatal stroke) occurs in about one of every 4,000 live births. Stroke also can occur before birth.

Improved diagnostic techniques such as magnetic resonance imagining and vascular ultrasound have made it possible to confirm that a stoke has occurred when it was only suspected before. Because of these advances, experts now believe that a significant number of cerebral palsy cases may be due to strokes before or right after birth.

The most common underlying risk factors for childhood stroke are sickle cell disease and congenital or acquired heart disease. The incidence of the two main types of stroke (ischemic and hemorrhagic) is different in adults and children. According to the statement, 80-85% of adult strokes in Western countries are caused by a blood clot (ischemic). In contrast, in children about 55% of strokes are ischemic and the other 45% are hemorrhagic (bleeding in the brain).

Source: Stroke Connection; Nov/Dec 2008

"Celebration of Life" Event ~ Support Jessica & Baby Sofia

Written by: Heidi Ponagai

Jessica is an APS patient and her daughter, Sofia was born very prematurely due to what sounds like CAPS.

Jessica's family is holding a private fundraiser on December 17, 2009.

If you live in the Encinitas area in California and are available for an evening out, then consider attending the event which is being held at Oggi's Pizza and Brewing Company.

The event is open to anyone and according to the flyer will include drinks, music, a raffle/auction, and an all around good time!

The APSFA sent along printed materials as well as some donated items for their auction.

To read Jessica's story and meet baby Sofia please visit their website:

www.helpjessicaandsofia.com/

For information about the event, please visit event page and download the flyer: http://www.helpjessicaandsofia.com/celebration-of-life-event-change-of-date--venue.html

My Silent Disease

Poem by: Lisa Odell

People look at me and say I look great,
I look at me and I question my fate.
Is it a good day, or one that is grand,
Or is it a day that I must reach for a hand.

With pain and new issues that come all the time,
Each case being different, it's so hard to define.
Each time there's an answer, a new problem arises.
Busy attacking it goes, leaving behind new surprises.

Life without answers, I'm stubborn for sure
I've out lived predictions with no hope for a cure.
So, you look at me and say I look fine,
As this disease steals a life that is no longer mine.

My family so suffers; yes I always see,
All the illness and anguish they suffer with me.
But others aren't looking because they can't see,
This "Silent Disease" that keeps attacking me.

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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.

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We have many autumn inspired baskets and bouquets that are now available, as well as fresh flowers for every occasion! So, check out our site and support the APSFA at the same time.

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