ANTIPHOSPHO...WHAT?

APS Foundation of America, Inc. Newsletter

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The Gift of the Blue Balloon ~ Daniela's Story

Submitted by: Daniela Kowal

From my experience of losing a baby, I have learned that if you keep your heart and mind receptive, you will receive signs and gifts in your life. This is my story of one of many signs that I have received.

I was diagnosed with APS when I suffered a mild stroke at 13 years of age. While as a teenager, I was upset at my diagnosis, I now look at it to be a mixed blessing of sorts. Because of all my health issues, I had decided to become a nurse to help others, and I love my profession. When the time came to have my first child, I felt empowered to know that my doctors and I could take the appropriate measures to prevent a fetal loss. There was a clear advantage to know beforehand. It is usually after a few losses that most women discover they have APS.

My daughter was born late spring in 2002 at 37 weeks gestation, strong and healthy. The minor problems with the pregnancy consisted of intra-uterine growth restriction, and painful vasculitis in my hands in the third trimester. My daughter is an amazing, bright child with so much love for life. She fills our lives with love and happiness. A couple years later, my husband and I decided to try for another child, and in January of 2005 we found out we were expecting. We were thrilled and looking forward to having this baby. However, my body began succumbing to the stress of APS and carrying a child in early April.

One morning, I woke up with a severe headache, blurriness in vision, and joint pains. The symptoms then progressed over the next couple of days to chest pains, shortness of breath, and vomiting. I was misdiagnosed with a nocturnal migraine, and then gastric reflux. I ended up in ICU with extremely elevated liver enzymes and plummeting platelet values. The doctors were able to pull me out of this dangerous spiral with high dose IV steroids. I remained in the hospital for 11 days and was sent home when my labs were back to normal. I felt so grateful because I was alive and still pregnant and almost 20 weeks along. Four more weeks and my baby would be considered viable. However, I was worried. I had felt that the baby must have endured quite a bit and may have suffered some consequence from this.

Two weeks later, my placenta erupted, and I found myself back in the hospital. My body was unable to carry my little son anymore. The stress was far too great. Cramping began, my water broke, and labor was initiated. I hemorrhaged considerably and received 6 units of blood total. Blood poured out of me like buckets of water. Gabriel was born on May 1st at 7:21 am in the morning. He was almost 22 weeks gestation and was beautiful and perfect in every way. He had my nose and my eyes, my husband's chin and face. He had blonde eyebrows and fuzzy hair. He looked a lot like his big sister. I held him in my arms for hours. My womb was to be a place of safety and comfort, and instead, it expelled him at a fragile point in his life. Feelings of being a failure as a mother consumed me, and I felt inadequate that I was unable to protect this child.

We planned a funeral for our son and I never thought that I would have grave plots for my family at such a young age. A friend of my mother's made a beautiful white gown for Gabriel to wear. I dressed him in it and held him one more time before placing him in his tiny coffin. Thoughts emerged of ways to include Ava for her brother's funeral. How was I to provide a healthy concept of death to her? The idea of the balloon emerged.

It was decided that Ava would release a baby blue balloon for her baby brother to receive in heaven, and to symbolize Gabriel's crossing over to the afterlife. She was to hold onto a pink balloon to represent her soul here,

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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
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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.

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

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

Spring is finally here and we will be getting ready for APS Awareness Month in June. It is mind blowing to think that in June we will turn 3 years old!!

I would like to thank everyone who donated to decorate our tree during the 2007 holiday season! Because of your generous donations, we were able to raise $1095.00! The Giving Tree holds a special meaning for the members of the APS Foundation of America, Inc and the community it serves. And since the Giving Tree was such a big success, we will be making this an annual tradition.

The APS Foundation of America actively works with our medical advisors and their respective facilities to educate the community and healthcare professionals about APS. We have been contacting various newspapers and media sources to get the word out about APS and the foundation.

We have a wonderful volunteer, Sandra, who made the APSFA a table top wishing well to use for collection of donations at health fairs, seminars and conferences. We think it turned out splendidly and can't wait to use it. You can see pictures of the wishing well at: http://photos.apsfa.org/ If you would like to use it for a private fundraising event, for the APSFA, please contact us and we will make arrangements to get it to you.

Heidi, our webmaster, has been making some changes to the foundation webpage. We hope you like them and they help you to navigate the site easier. Please check it out at www.apsfa.org and tell us what you think. Also be sure to check out our Cafepress site at www.cafepress.com/apsfoundation. We will be adding new designs in the upcoming months.

Before I forget, our support forum is still growing by leaps and bounds. We are over 1,600 members strong and have an average of 2,152 posts per month! Talk about a very active support forum.

Once again, I hope this newsletter finds you in the best of health and with a perfect INR level.

Sincerely,

Tina Pohlman

President & Founder

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Warfarin Resistance

Written by: Thomas L Ortel, MD, PhD

Warfarin is an oral anticoagulant that is used for the prevention and treatment of blood clots in arteries and veins. Warfarin acts by interfering with a vitamin K-dependent process that is essential for the production of several of the blood clotting proteins (known as factors II, VII, IX and X). By lowering the levels of these blood clotting proteins, the patient's blood takes longer to form a clot in a specific laboratory test (reported as the INR, or international normalized ratio). The higher the INR rises, the lower the levels of those blood clotting proteins drops. One can reverse the effect of the INR by stopping the warfarin, or by increasing the amount of vitamin K in the diet. Many other things can affect warfarin and the INR, but this article will focus on the question of "What is warfarin resistance?"

"Warfarin resistance" can mean different things, depending on the laboratory results and the clinical situation. First, some patients may be taking warfarin, but the INR does not elevate as expected. This could be due to several problems:

- Not taking the warfarin: This is an easy one to check on, since the doctor can measure an actual warfarin level and confirm whether or not the drug is actually getting into the bloodstream.
- Problems with warfarin absorption: Some patients may have problems with malabsorption syndromes, chronic diarrhea, or have a 'short gut' after extensive surgery to remove a portion of the bowels. In this case, the warfarin is being swallowed, but just doesn't get absorbed. Again, a warfarin level could help sort this one out.
- Eating foods high in vitamin K content: Some foods contain very high amounts of vitamin K, and eating these can lead to needing more warfarin to achieve the same INR.
- Genetic resistance to warfarin: Recently, polymorphisms present in two genes that code for proteins involved in the metabolism of vitamin K ("VKOR" and "CYP 2C9") have been described which can have an impact on the amount of warfarin an individual patient might need. In general, these do not reflect large differences in the dose between different individuals, but they do identify certain individuals for whom 5 mg a day of warfarin may be too much. On the other hand, much more rarely, there are certain individuals who truly require very large doses of warfarin to get their INR into the target therapeutic range (for example, a patient may need more than 20 mg of warfarin every day to keep the INR between 2 and 3).

> ***"The higher the INR rises, the lower the levels of those blood clotting proteins drops. One can reverse the effect of the INR by stopping the warfarin, or by increasing the amount of vitamin K in the diet."***

The second type of "warfarin resistance" refers to patients who have a thrombotic complication even though they are taking the warfarin as instructed and have an INR that is in the correct therapeutic range. For example, a patient with an INR of 2.5 has a NEW deep vein thrombosis. This could be due to a couple of problems:

- With certain hypercoagulable states, the tendency to develop a clot overcomes the anticoagulant effect of the warfarin. This can occur in patients with cancer as well as certain other clinical situations, including some patients with antiphospholipid syndrome. When this occurs, it is important to confirm that the patient's INR is within the target therapeutic range, which would indicate whether the patient has truly 'failed' warfarin therapy. For those patients who have truly 'failed' warfarin, the doctor can either increase the target therapeutic INR or switch to a different anticoagulant (for example, a low molecular weight heparin, like enoxaparin).
- For a small subset of patients with antiphospholipid antibodies, the INR is abnormal even when the patient is not taking warfarin (because of antibody effect on the coagulation assay). In these cases, the INR does not accurately represent the effect of warfarin, and the patient may be insufficiently treated. A different test, such as the chromogenic factor X, might be useful for monitoring warfarin, or the patient may need to be treated with an anticoagulant that does not need to be monitored, such as a low-molecular weight heparin.

In conclusion, warfarin "resistance" can refer to several different types of problems, some of which require adjustments or alterations to the warfarin dosing, and some of which require changing from warfarin to a different anticoagulant. It is important that a doctor carefully document what is happening when identifying a patient as being 'warfarin resistant'. Within the next couple of years, there should be new oral anticoagulants that can be substituted for warfarin; in the meantime, telling a patient that he/she cannot use warfarin results in the patient needing to give themselves a shot once or twice a day.

REFERENCES

1. Lara LF, Delgado LL, Frazee LA, Haupt KM, Rutecki GW.A subtherapeutic international normalized ratio despite increasing doses of warfarin: could this be malabsorption? Am J Med Sci. 2000 Sep;320(3):214-8.
2. Anderson JL, Horne BD, Stevens SM, Grove AS, Barton S, Nicholas ZP, Kahn SF, May HT, Samuelson KM, Muhlestein JB, Carlquist JF; Couma-Gen Investigators. Randomized trial of genotype-guided versus standard warfarin dosing in patients initiating oral anticoagulation. Circulation. 2007 Nov 27;116(22):2563-70.
3. Moll S, Ortel TL. Monitoring warfarin therapy in patients with lupus anticoagulants. Ann Intern Med. 1997 Aug 1;127(3):177-85.
4. Franco V, Polanczyk CA, Clausell N, Rohde LE. Role of dietary vitamin K intake in chronic oral anticoagulation: prospective evidence from observational and randomized protocols. Am J Med. 2004 May 15;116(10):651-6.
5. White RH, Zhou H, Romano P, Mungall D. Changes in plasma warfarin levels and variations in steady-state prothrombin times. Clin Pharmacol Ther. 1995 Nov;58(5):588-93.

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grounded on earth. At the end of the services at the cemetery, my daughter announced, "This balloon is for my baby brother up in heaven.", and let it go. Everyone watched as the balloon shot straight up into the sky without wavering. And then, the blue balloon became a speck in the bright blue skies and disappeared. My daughter ran around Gabriel's grave, smiling and joyfully playing with her pink balloon as my husband and I could barely see through our tears.

Because I had become so sick and it was thought that this outcome would occur with each subsequent pregnancy, I was told by my rheumatologist and ob that pregnancy was too risky for me, and was highly advised against it. I had to deal with two losses; the loss of a child and the loss of having another.

September 6th rolled along. This was Gabriel's due date and a date in which a flicker of hope began. I found a name of a rheumatologist through a scientist friend. The doctor was out of state, and a notable researcher for APS. I made the appointment to get a second opinion.

At the rheumatologist's office, I told my story to the doctor. When I was finished, he asked what brought me to his office. I thought of everything that I went through, and realized how absurd it's going to sound that I still had my dream of having another child, but asked for his opinion. After all, if that chapter needed to be closed in my life, I needed to know. To my wonderful surprise, I got that amazing answer. "Yes". He has had a handful of patients who have tried after having similar episodes like mine, and they all have had successful outcomes. There are always risks, but that door in my life stayed opened and once again, I felt hope. I had hope. I went for another opinion with a maternal fetal medicine doctor who specializes in clotting disorders. He too said that magical word. *yes*.

It was the beginning of April in 2006. My daughter had dance class. The day was cloudy and misty. It had been exactly a year since my admission to the hospital. I spent most of that morning miserably crying. I got my daughter ready, and as I was driving down our long driveway, something blue caught my eye. As we approached it, I stopped the car, and picked up a baby blue colored balloon that was nestled in the ground. I gave it to my daughter with a smile. The balloon floated again in the car. The mist and air pressure outside must have kept it grounded. I asked Ava if she remembered the blue balloon she let go for her baby brother. She nodded yes. I responded by telling her that Gabriel was thinking of her and sending one back so that she could play with it. With this, Ava smiled and snuggled with the balloon. After dance, she played joyfully with the balloon at home. After all, her baby brother had sent it down to her!

The next month I became pregnant. In January, in my 37th week of pregnancy, I gave birth to a healthy son, Ethan Gabriel. Overall, I had an uneventful pregnancy and delivery. We were truly sent a gift from heaven.

Occasionally, I will open up the box of Gabriel's things that I received at the hospital. I lovingly touch his hospital bracelets, his pictures, his footprints and his outfit that he wore. I know I will have a good cry because I miss him so. I also look at the blue balloon which I carefully folded in this box and I think of hope. I look at my son, Ethan, and remember that this is the child I was told that I could not have.

Miracles do happen, and even if someone passes from this life, they are still very much a part of us, a fiber of our being. If we keep our eyes open, they will manifest themselves to us through the little things in every day life. It was more than mere coincidence that an identical color balloon would find itself on our property on my one year hospitalization anniversary and on a day that I was emotionally distraught. Nor was it a coincidence that a month later, a baby boy's life began in my womb and I was to experience pregnancy once again; this time with a strong, safe place for my child to thrive in.

My daughter may have had to let one baby brother go up to heaven, but she received another baby brother that was meant to be here on earth. Gabriel made sure to give us this message by 'sending' us the gift of a blue balloon.

Stimulus Payments

Submitted by: Tina Pohlman

Instructions for Low-Income Workers, Recipients of Social Security and Certain Veterans' Benefits.

The IRS has created a page on their website dedicated to addressing questions about promised rebate checks included in the President's new Economic Stimulus Package, which includes information for Social Security beneficiaries. The information claims that **"the stimulus payments will not count toward or negatively impact any other income-based government benefits, such as Social Security benefits, food stamps and other programs"**.

Individuals who might not otherwise be required to file a 2007 tax return will need to file a return this year to receive the stimulus payment. The return must show at least $3,000 in qualifying income. In other words, low-income workers who had at least $3,000 in earned income in 2007 but do not otherwise earn enough to be required to file a federal tax return need to file a return in order to get the stimulus payment. Likewise, **Social Security recipients and veterans who might not otherwise need to file a tax return must do so to receive the economic stimulus payment**.

For further information, visit the IRS website at www.irs.gov or call 1-800-829-1040.

Preventative Pointers for APS Patients Having Surgery

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

Management of the APS patient before, during, and after even minor surgery requires special thinking and planning. As blood flow changes to an area when a patient is lying down or position for surgery, there are general approaches to make all procedures safer. Surgery is associated with anesthesia of different types, and any patient knows the temperature is cool in operating rooms. Decreasing blood flow to the surgical site to make surgery easier, lack of usual activity (being supine in a bed), and having a predisposition to make blood clots already puts the APS patient at more than the usual risk of having a blood clot after surgery. A classic lesson students in healthcare learn early in their studies is that a clot occurs if "Virchow's Triad" is met-a state of low blood flow called stasis, injury to the blood vessel lining cells (endothelial cells), and a hypercoagulable state-patients with APS may already have the latter 2 predispositions prior to the "second hit" of surgery and anesthesia.

The guidelines are experience –based for individual surgery types more than true evidence-based medicine. A reference list is appended at the end for patients to provide to their physicians to foster discussion, and complements some of those cited in the "Bridge Therapy" article elsewhere in this issue.

General Points. Surgery is always best when planned ahead, or elective, rather than done as an emergency. The patient should aspire to optimize lung function and body weight with physician guidance to reduce risks of anesthesia and surgery (which includes infection, lung function compromise, and blood clots). Even a small weight loss of 10 lbs and of course, stopping smoking totally or at least for several weeks prior to surgery can have beneficial effects on outcomes. Planning surgery at a time when antiphospholipid antibodies are low or normal would be optimal, but this caveat can't always be met. The physician/surgeon should choose a procedure that will require the minimal time off aspirin and/or off warfarin for the APS patient. Minimizing or avoiding tourniquet use for some procedures is very important in APS patients, as their blood vessel lining cells are often poised to support clotting more easily than non-APS patients. Some surgeries generate or upregulate coagulation-inciting proteins called "tissue factors" more than other surgeries. Extreme caution to avoid infection is a "must", as infection all by itself can activate the clotting (coagulation) system.

Specific Management Points. Most recommendations are divided into the preoperative (5 days or so before the surgery) and the perioperative (day before/during surgery) period, and then the post-operative period. Stopping low-dose (81 mg a day) or regular (325 mg a day) aspirin 3-10 days before surgery is a usual first approach. As this is only a guideline, the patient should discuss this with the physician/surgeon and work out a specific timetable to stop. Some APS patients may also be on nonsteroidal anti-inflammatory agents, which can also affect platelets, and these agents are usually stopped ahead of time, too.

THROMBOPROPHYLAXIS REGIMENS

GEN SURGERY:
- LDU HEPARIN
  - 5000 U q 8-12hr
  - START 1-2 day before
- LMW HEPARIN
  - 30 MG q 12hr
  - START 1-2hr after
  - Or 40 MG q 24hr
  - START 1-2hr before

ORTHOPEDIC SURGERY:
- LDU HEPARIN
  - 5000 U q 8-12hr
  - START 12-14hr after
- LMW HEPARIN
  - 30 MG q 12hr
  - START 12-24hr after
  - Or 40MG q 24hr
  - START 10-12hr before

q = every hr = hour(s)

For the APS patient who is anticoagulated on warfarin (Coumadin), the guidelines vary relative to the type of surgery, and are highly individual. The usual approach is to stop warfarin approx 5 days prior to surgery (optimally to minimize the time off warfarin where possible), rather than to use vitamin K reversal treatment to "undo quickly" the anticoagulation.

Then, depending on the nature and the site of the procedure/surgery, the approach is to use low dose unfractionated (LDU) heparin, or low molecular weight (LMW) heparin injection regimens such as those shown in the Insert for General Surgery and for Orthopedic Surgery. Preventing a blood clot is called "thromboprophylaxis".

During the procedure (where possible as it depends on the nature and site of the surgery), or in the immediate postoperative period, the use of anti-venous thrombosis (anti-leg clot) pneumatic (air) compression sleeves or cuffs is recommended. These devices alternate pressure on the leg veins to avoid letting blood sludge in the veins, and they should be set to inflate frequently. They in themselves in the APS patient may not prevent clots, and are often used with additional prophylaxis (prevention) using one of the heparin regimens referred to above.

The patient and the physician/surgeon should discuss the exact approach to be used, and this is often varied based on the procedure. In APS patients, even minor procedures such as podiatric surgery places them at risk, and the trend is to suggest that blood clot prophylaxis be more widely used. This is a growing area of concern in APS patients.

Some people mistakenly believe that if the platelet count in an APS patient is <100,000, that a clot can't occur and this is erroneous-low platelets (thrombocytopenia) don't protect against clotting. Early ambulation of the APS patient from a surgery is helpful but is not 100% insurance a clot won't occur. The additional effects of having to wear a cast or a compressive bandage also has to be taken into consideration in the APS

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Mark Hackley: A Country Singer's Life-Changing Story

Written by: Joanne DiMaggio

For years, country singer/song writer Mark Hackley performed his songs without a glitch. That all changed in June 2006. What began innocently enough as a routine performance of a private concert in northern Virginia soon turned into a life-threatening event that would change Mark's life forever.

Hackley remembers standing in an awkward position during the three-hour concert—a reaction to the new pair of cowboy-style, calf-high boots he was wearing—which unbeknown to him was cutting off or reducing the blood flow to his calf. Although he felt a dull pain in his left calf, he shook it off and continued performing.

By the time he returned to home after the show, the pain had moved from his calf to his chest. "It felt like serious muscle cramps in my chest wall," Hackley recalled. "I never suspected it to be a blood clot in my lung. It seemed like the intense pain came from outside of my ribs, not from inside my lung."

Not realizing the increasing seriousness of the situation, Hackley tried to sleep, but the next morning after a restless night, he decided to seek medical attention. His doctor recognized the symptoms and tested for a pulmonary embolism (PE). That is when a clot was discovered in Hackley's right lung and he was admitted to the emergency room where he was immediately treated with anticoagulant therapy.

Like most individuals who experience a deep vein thrombosis (DVT) or PE, Hackley was first treated with heparin and then with warfarin (Coumadin), which he would continue to take for a year after the clot.

While in recovery, Hackley thought a lot about DVT/PE. If he didn't recognize the symptoms, he wondered how many other people experience a PE and don't realize what it is. He thought about what may have triggered the condition in him and recalled that months earlier he had suffered a severe muscle pull in his upper leg during a softball match. It was only after his diagnosis that he learned that sitting for long periods of time, injuries, and surgeries are all possible culprits for blood clots.

Thinking about the 300,000 Americans who die each year from PE, Hackley began to ponder whether there was some way he could help reduce that number by developing a national platform to tell his story.

"I wanted people to know that you don't have to be an old man to suffer a serious blood clot," Hackley said, who was 45 at the time. "Having a DVT or PE is a very serious situation and I want to help increase awareness of both conditions so that others may prevent blood clots before they happen."

Hackley's second chance at life energized him to write and record new songs, which culminated in a new CD entitled *Hurricane*. The fact that the blood clot formed during one of his performances only confirmed in his mind that he could use his talent to create an awareness of the warning signs of DVT/PE.

To coincide with March being DVT Awareness Month, Hackley created an awareness poster that told his story and included a tear-off card with facts about DVT/PE, tips on prevention, and his fundraising efforts to increase awareness of the danger of blood clots. Using his own money, Hackley sent out nearly 1000 of these posters to hematologists across the country, asking them to display the poster in their offices to help spread the message about DVT/PE to people in their community. Hackley also sent each doctor a complimentary copy of *Hurricane*.

As part of his fundraising commitment, for every MP3 download and CD sold from Hackley's website, he is donating 15 percent of the retail sale to the National Alliance for Thrombosis and Thrombophilia (NATT). He is hopeful that in addition to helping people recognize the seriousness of blood clotting disorders through his posters, the sale of these CDs will generate what he hopes will be a considerable donation to help NATT in their work of spreading awareness about DVT/PE.

Hackley has been healthy since his blood clot was diagnosed and treated and today lives with his family in the mountains of Virginia where he continues to write, perform and records his own country music.

"After what I have been through, I truly believe many people would ride out the pain and not seek medical attention in time," Mark said. "If they do, many of these people will die. I'm a cowboy and I tried to ride it out that night, but I'm so glad I saw my doctor when I did. It probably saved my life."

For more information on Mark Hackley's story and music, visit www.markhackley.com.

Bridge Therapy: Antiphospholipid Antibody Syndrome (APS)

Written by: Liza Alarid, Pharm. D. Candidate
University of Colorado at Denver and Health Sciences Center School of Pharmacy
Reviewed by: Al Lodwick, RPh, MA

Clinical Ramifications

Past clinicians faced a conundrum; what is the ideal treatment strategy for patients receiving chronic warfarin therapy when therapy needs to be interrupted for surgical or invasive procedures? Patient's have a potential risk of bleeding complications while on warfarin. On the other hand, if warfarin is abruptly halted APS patients are at increased risk of clotting complications innately due to their disease state and secondly they face the added risks involved with the surgical or invasive procedures.

What is Bridge Therapy?

Bridge therapy, is a non-FDA approved treatment measure commonly used in patients at risk for clotting who must halt warfarin therapy when an invasive or surgical procedure is required. Bridge therapy, recommended by numerous consensus organizations such as the American College of Chest Physicians (ACCP)[8], involves, as the word implies a therapy bridge. The addition of subcutaneous full dose low molecular weight heparin, or unfractionated heparin allows clinicians to preoperatively halt warfarin approximately 5 days prior to the surgical or invasive surgery. Halting warfarin, reduces the patients International Normalized Ratio (INR), the indicator of the level of anticoagulation, to near normal levels reducing bleeding complications, while low molecular weight heparin (LMWH), or unfractionated heparin (UH) protect patients against clotting with a lower risk of bleeding complications. Postoperatively bridge therapy ensures the patient can resume warfarin until the level is safely within a therapeutic range thus reducing clotting complications. LMWH and UH are administered subcutaneously and rapidly ensure that patients are protected from clotting.. Warfarin on the other hand takes 3-5 days to be therapeutic thus bridging protects patients until warfarin is safely therapeutic at which time the patient may discontinue LMWH or UH.

Steps of Bridge Therapy[8]

1. Patient maybe instructed to hold warfarin approximately 5 days before procedure
2. Patient will start a full dose of low molecular weight heparin or unfractionated heparin 3-4 days before surgery
3. Patient will take the last dose of low molecular weight heparin or unfractionated heparin either 12-24 hours before the procedure
4. Patient will resume low molecular weight heparin or unfractionated heparin 12-24 hours postoperatively and continue until INR therapeutic
5. Resume warfarin 12-48 hours postoperatively

To Bridge or Not To Bridge

According to the consensus guidelines from the American College of Chest Physicians (ACCP) bridge therapy is determined according to the risk of thrombosis or stroke and secondly according to bleeding risk associated with the surgical or invasive procedure. APS patients are considered a high-risk patient population according to ACCP guidelines. The APS population requires bridge therapy if procedure involves a high risk of bleeding complication. The following surgical or invasive procedures warrant bridge therapy according to ACCP consensus guidelines. [8]

Procedures Warranting Bridge Therapy

1. Neurosurgery
2. Orthopedic joint procedures (knee, hip)
3. Abdominal or pelvic surgery
4. Major ear, nose, throat or oral surgery
5. Endoscopy or colonoscopy with biopsy
6. Prolonged general anesthesia with intubation
7. Epidural anesthesia

Bridge Therapy Assessment

Heparin

Since the 1930s, clinicians have used (UH) for the prevention and treatment of thrombosis.[9] For the prevention of venous thromboembolism, UH is given by subcutaneous injection in the abdominal fat layer. The typical dose for prophylaxis is 5000 units every 8 to 12 hours. Administration of UH requires close monitoring because of the unpredictable anticoagulant response among patients.[9,10] Several tests are available to monitor UH therapy, the most widely used is the activated partial thromboplastin time (aPTT). The therapeutic range of aPTT is traditionally considered to be 1.5 to 2.5 times the mean normal control value. [9,10]

Side effects:

The most common side effects are bruising, local irritation, mild pain, and swelling at the site of injection. Risk of major bleeding is minimal, with the most frequent sites being the gastrointestinal, urinary tract, or soft tissues. Lastly, a rare but severe side effect is heparin-induced thrombocytopenia (HIT) which is an autoimmune destruction of platelets.

Low molecular weight heparins

Developed in the 1980's, LMWHs are fragments of UH.[9] More recent large studies have shown no significant differences in the efficacy or safety of LMWHs vs UH. LMWHs are given by subcutaneous injection in the abdominal fat layer. The typical dose for prophylaxis is based upon the product. Administration of LMWHs do not require close monitoring since they have a predictable anticoagulant response among patients.[9,10]

Side Effects:

As with UH, the most common side effects are bruising, local irritation, mild pain, and swelling at the site of injection. Risk of major bleeding is also minimal, with the most frequent sites being the gastrointestinal and urinary tracts, as well as soft tissues. The occurrence of heparin-induced thrombocytopenia (HIT) occurs less frequently than UH.

Summary

APS patients should be offered bridge therapy. Overall, a regimen with LMWH is associated with a low risk of clotting, major bleeding complications, and is feasible for

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patient.

When to resume warfarin and/or aspirin after periopertive/postoperative heparin therapy, is determined by the nature of the surgery, the physician/surgeon's comfort zone, and the needs of the individual patient. A balance has to be achieved between the risk of bleeding at a surgical site vs. the risk of having a blood clot after surgery, which is why these articles present guidelines and suggestions. A useful URL for patients is that of the Hospital for Special Surgery in New York, http://www.hss.edu, which has excellent patient information re: preparing for different surgeries and experience in dealing with APS.

In the immediate postoperative period, *any deviation from an expected course or progress* in an APS patient should raise the question in physicians/surgeons managing them whether an investigation is necessary to determine whether a blood clot (thrombosis) has occurred. "An ounce of prevention here may be worth a pound of cure."

REFERENCES:

Erkan D et al: Perioperative medical management of APS: HSS surgery experience, review of literature, and recommendations-case series. J RHEUM 2002;29:843-9.

Ruiz-Irastorza et al: Antiphospholipid antibodies (aPLs)-a systematic review of secondary thromboprophylaxis in pts with antiphospholipid antibody syndrome (APS). ARTHRITIS CARE RES 2007;57:1487-95

O'Neill KM: Secondary prevention: warfarin rx in APS. CURR RHEUM REP 2007;9:187,

Agaba AE: APS: a series of surgical emergencies and the current evidence for its management. ANN R COLL SURG ENGL 2006;888:370-4.

Schnitz WM, Lister KA, McCarty GA: Management of aPL positivity and elective orthopedic procedures. LUPUS 1992;1:187-9.

APSFA To the Rescue

Written by: Seren Estrada

Balancing a family, chronic illness and college carries its own challenges. One of those challenges is being able to attend classes during an APS flare. In the past month, my immune system was bombarded by the flu, bronchitis, and migraines. It took longer to recover from these than what was normal for me, and as a result I missed over a week of classes. I was able to obtain a doctor's note for my absences, however, not all of my professors w ere understanding enough to excuse me and allow me to turn in my assignments via email from home. In one class in particular, this was the difference between an 'A' and failing.

Since I felt that my insurgence of illnesses was brought on by immunosuppression (used to treat my APS), I felt that I was at more of a disadvantage than some of my peers. I contacted the Disabled Students Services Office at my university, and applied for accommodations that were applicable to my situation. I asked for excused absences during a flare, and permission to turn in homework via email if I could not hand it in personally.

Feeling frustrated and overwhelmed, I turned to the APSFA for help and advocacy. President Tina Pohlman was able to write a letter on my behalf entailing exactly what APS is and what could happen during a flare. This letter was especially helpful since no one at the Disabled Student Services Office had ever heard of APS. After gathering a better understanding of APS from the letter, the DSSO's Assistant Director told me how they do accommodate for people who experience illnesses with flares.

Thanks to the support of the APSFA, I expect to continue my education with the help of the DSSO. It also goes to show that the APS Foundation of America, Inc is truly dedicated to advocating for people with APS.

A Recipe From the "On Coumadin" Section of the Cookbook
Homemade Hummus

Hummus is an excellent appetizer and can be served with pita, veggies or crackers.

Servings = 6 | Serving size =1/2 cup

This recipe can be multiplied by 2.

The hummus keeps well in the refrigerator for 4 – 5 days if tightly covered.

INGREDIANTS

2 - 15 ounce cans of garbanzo beans

3 cloves garlic

2 Tbsp tahini

1/3 cup fresh lemon juice

1 cup non-fat yogurt

DIRECTIONS

Place all ingredients in a food processor and process until almost smooth. The texture should be like overcooked oatmeal.

Chill.

Nutrition Facts

Serving size: 1/2 cup | Servings 6

Calories 201 | Calories from Fat 35

Amount Per Serving (% Daily Value)

Total Fat 4g (6%) | Saturated Fat 1g (0%)

Monounsaturated Fat 1g | Trans Fat 0g

Cholesterol 1 mg (0 %) | Sodium 396 mg (17 %)

Total Carbohydrates 33g (11%) | Sugars 3g

Dietary Fiber 6g (23%) | Protein 9g

Vitamin A 1% | Vitamin C 19 % | Calcium 14% | Iron 12%

Vitamin K 0 mcg | Potassium 354 mg | Magnesium 49 mg

Source:
http://www.drgourmet.com/recipes/extras/hummus.shtml

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daily outpatient administration.

Citation

1. Nutescu EA, Wittkowsky AK, Dobesh PP, Hawkins DW, Dager WE. Choosing the appropriate antithrombotic agent for the prevention and treatment of VTE: a case-based approach. Ann Pharmacother. 2006 Sep;40(9):1558-71. Epub 2006 Aug 15. . [Cited 2008 Jan 27]. Available from : URL: http://www.ncbi.nlm.nih.gov/entrez/utils/fref.fcgi?PrId=3051&itool=Abstract-def&uid=16912250&db=pubmed&url=http://www.theannals.com/cgi/pmidlookup?view=long&pmid=16912250

2. Thomas R. Hypercoagulability syndromes. Arch Intern Med 2001;161:2433–2439. [Cited 2008 Jan 27]. Available from : URL: http://archinte.ama-assn.org/cgi/content/abstract/161/20/2433?ck=nck

3. Muscal E, Brey RL. Neurological manifestations of the antiphospholipid syndrome: risk assessments and evidence-based medicine. Int J Clin Pract. 2007 Sep;61(9):1561-8. Epub 2007 Jun 26. [Cited 2008 Jan 27]. Available from : URL: http://www.ncbi.nlm.nih.gov/pubmed/17596187?ordinalpos=1&itool=EntrezSystem2.PEntrez.Pubmed.Pubmed_ResultsPanel.Pubmed_RVDocSum

4. Ruiz-Irastorza G, Khamashta MA. The treatment of antiphospholipid syndrome: A harmonic contrast. Best Pract Res Clin Rheumatol. 2007 Dec;21(6):1079-92. [Cited 2008 Jan 27]. Available from : URL: http://www.ncbi.nlm.nih.gov/pubmed/18068863?ordinalpos=1&itool=EntrezSystem2.PEntrez.Pubmed.Pubmed_ResultsPanel.Pubmed_RVDocSum

5. Wahl DG, Bounameaux H, de Moerloose P, Sarasin FP. Prophylactic antithrombotic therapy for patients with systemic lupus erythematosus with or without antiphospholipid antibodies: do the benefits outweigh the risks? A decision analysis. Arch Intern Med. 2000 Jul 10;160(13):2042-8. [Cited 2008 Jan 27]. Available from : URL: http://www.ncbi.nlm.nih.gov/pubmed/10888978?ordinalpos=3&itool=EntrezSystem2.PEntrez.Pubmed.Pubmed_ResultsPanel.Pubmed_RVDocSum

6. Agnelli G, Prandoni P, Santamaria MG, Bagatella P, Iorio A, Bazzan M, Moia M, Guazzaloca G, Bertoldi A, Tomasi C, Scannapieco G, Ageno W; Warfarin Optimal Duration Italian Trial Investigators. Three months versus one year of oral anticoagulant therapy for idiopathic deep venous thrombosis. Warfarin Optimal Duration Italian Trial Investigators. N Engl J Med. 2001 Jul 19;345(3):165-9. [Cited 2008 Jan 27]. Available from : URL: http://www.ncbi.nlm.nih.gov/sites/entrez

7. Ridker PM, Goldhaber SZ, Danielson E, Rosenberg Y, Eby CS, Deitcher SR, Cushman M, Moll S, Kessler CM, Elliott CG, Paulson R, Wong T, Bauer KA, Schwartz BA, Miletich JP, Bounameaux H, Glynn RJ; PREVENT Investigators. Long-term, low-intensity warfarin therapy for the prevention of recurrent venous thromboembolism. N Engl J Med. 2003 Apr 10;348(15):1425-34. Epub 2003 Feb 24. [Cited 2008 Jan 27]. Available from : URL: http://www.ncbi.nlm.nih.gov/pubmed/12601075?ordinalpos=5&itool=EntrezSystem2.PEntrez.Pubmed.Pubmed_ResultsPanel.Pubmed_RVDocSum

8. Hirsh J, Raschke R. Heparin and low-molecular-weight heparin: The Seventh ACCP Conference on Antithrombotic and Thrombolytic Therapy. Chest 2004;126:188S–203S. [Cited 2008 Jan 24]. Available from : URL: http://www.ncbi.nlm.nih.gov/pubmed/15383472?ordinalpos=4&itool=EntrezSystem2.PEntrez.Pubmed.Pubmed_ResultsPanel.Pubmed_RVDocSum

9. Levine MN, Raskob G, Beyth RJ, Kearon C, Schulman S. Hemorrhagic complications of anticoagulant treatment: the Seventh ACCP Conference on Antithrombotic and Thrombolytic Therapy. Chest. 2004 Sep;126(3 Suppl):287S-310S. [Cited 2008 Jan 24]. Available from : URL: http://www.ncbi.nlm.nih.gov/sites/entrez

10. Dolovich LR, Ginsberg JS, Douketis JD, Holbrook AM, Cheah G. A meta-analysis comparing low-molecular-weight heparins with unfractionated heparin in the treatment of venous thromboembolism: examining some unanswered questions regarding location of treatment, product type, and dosing frequency. Arch Intern Med. 2000 Jan 24;160(2):181-8. [Cited 2008 Jan 24]. Available from : URL: http://www.ncbi.nlm.nih.gov/pubmed/10647756?ordinalpos=23&itool=EntrezSystem2.PEntrez.Pubmed.Pubmed_ResultsPanel.Pubmed_RVDocSum

11. Ansell J, Hirsh J, Poller L, Bussey H, Jacobson A, Hylek E. The pharmacology and management of the vitamin K antagonists: the Seventh ACCP Conference on Antithrombotic and Thrombolytic Therapy. Chest. 2004 Sep;126(3 Suppl):204S-233S. [Cited 2008 Jan 24]. Available from : URL: http://www.ncbi.nlm.nih.gov/pubmed/15383473?ordinalpos=12&itool=EntrezSystem2.PEntrez.Pubmed.Pubmed_ResultsPanel.Pubmed_RVDocSum

12. Bates SM, Greer IA, Hirsh J, Ginsberg JS. Use of antithrombotic agents during pregnancy: the Seventh ACCP Conference on Antithrombotic and Thrombolytic Therapy. Chest. 2004 Sep;126(3 Suppl):627S-644S. [Cited 2008 Jan 24]. Available from : URL: http://www.ncbi.nlm.nih.gov/pubmed/15383488?ordinalpos=1&itool=EntrezSystem2.PEntrez.Pubmed.Pubmed_ResultsPanel.Pubmed_RVDocSum

From the APSFA FAQ Page
"Do all APS Patients have the same symptoms?"

By definition, all patients with antiphospholipid syndrome have some type of blood clot, affecting either the arteries or the veins, or recurrent miscarriages or certain other complications during pregnancy. Other problems that may be seen in patients with antiphospholipid syndrome may include a particular type of rash (livido reticularis), low platelet

counts ('thrombocytopenia'), heart valve problems, certain fingernail changes, or other signs or symptoms. Lastly, some individuals may have elevated antiphospholipid antibody levels but be completely asymptomatic. In this situation, the antibody may have been detected by blood test results drawn prior to a surgical procedure, or for some other reason.

Do You Know Who I Am?
Written by: Richelle

Few people notice me for I am like a snake in the grass. My ways are cunning and baffling. I will take your heart and wreak havoc. I will take your brain and make it into mush. I enjoy catastrophe and heartache. I will take every child out of your womb. I will not give up. I will not give up until I have every last baby. I will creep in quietly. You won't notice me at first. People will think you are crazy and they will say mean things about you. You will think you are crazy too and you will fear what each day shall bring.

I will begin to show small signs of my presence. I will draw lacy patterns on your legs. Then I will move up to your kidneys. If that doesn't work, I will go straight for your heart. If you prove yourself strong, I will torture your brain. This is war. And I will shoot you with tiny little clots made from your own blood. If I don't succeed the first time, I will start over until I get it right. It's one big cycle. You just go through the arteries and the veins.

My name is APS. I will do everything I can to kill you. Your doctor may or may not know anything about me, or my powers. He will think I'm pretty benign, until I become more aggressive. How sad for you, it may be too late. How sad for your family. If your doctor does decide to fight me, then I become stronger. For no man can tame me. You can arm yourself with the best medications out there, but that won't stop me from trying to take you. If I really want your life, it's mine.

You'd better warn your family and friends, just incase I'm successful this time around. You should tell your doctor that, he is going to look like a fool when he realizes he should have listened to you, especially when your family decides to take him to court. Make sure you have your last will and testament ready, just incase. I may let you live a long life, but it may be a difficult one. Or I could take you tomorrow. Don't ever forget my name. It's Antiphospholipid Antibody Syndrome. But you can just call me APS!

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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: Gundersen Lutheran

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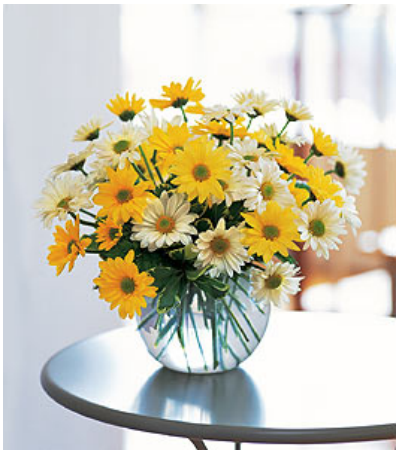

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