



ANTIPHOSPHO...WHAT?

APS Foundation of America, Inc. Newsletter

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Probiotics and Their Probable Effect on Warfarin

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What are probiotics? Probiotics are generally defined as live microbial organisms that are used medicinally to help improve the intestinal bacterial flora.[1] [2] Probiotics can be consumed as functional foods or as a supplement if they are in a capsule or pill form. The Food and Nutrition Board of the Institute of Medicine defines a functional food as, "Any food or food ingredient that may provide a health benefit beyond the traditional nutrients that it contains."2 An example of a functional food would be fortified milk.

Lactobacillus and *Bifidobacterium* genera are two of the most common types of bacteria found in probiotic supplements.

Potential benefits of probiotics:

Probiotics have been used to treat several different ailments including: diarrhea, inflammatory bowel disease, irritable bowel, lactose intolerance, and yeast infections.1 [3] [4] Probiotics work by attaching themselves to the walls of the intestine.[5] The probiotic bacteria then increase the number of good bacteria and fight harmful bacteria such as *salmonella*, *shigella*, and *E. coli*. [6] It is thought that probiotic bacteria may fight off harmful bacteria by acidifying the colon which prevents the growth of the harmful bacteria.6 Probiotics also restore the body's production of vitamin K and B vitamins in the intestine.

Potential drug interaction between probiotics and warfarin:

Warfarin works by interfering with the liver's synthesis of vitamin-K dependent clotting factors.[7] One of the main counseling points associated with warfarin therapy is about products/foods that might contain vitamin K and how they can counteract the effects of warfarin. If probiotic bacteria increase the amount of vitamin K, theoretically the patient would need more warfarin to inhibit the synthesis of the vitamin K dependent clotting factors. There have not been any studies done that have looked specifically at the effects of probiotics on warfarin; however, if the theory above is correct then a patient's INR would decrease if they started to take probiotics

while on warfarin therapy. Due to the increased production of vitamin K a patient's warfarin dose would need to be increased if the patient was going start or continue taking probiotics. Another important point to keep in mind here is that vitamin K is a fat soluble vitamin. Due to the fact that vitamin K is a fat soluble vitamin, the vitamin K is going to stay around longer.

Patient case: We have a patient at the anticoagulation clinic who is taking probiotics. One

"Probiotics can potentially interfere with warfarin therapy because probiotics produce vitamin K that is used by the body to produce clotting factors. A person who is taking probiotics may need to have their warfarin dose adjusted in order to reach a therapeutic INR."

thing that we have noticed about this patient is that not only is she taking probiotics but she is also taking several other herbal/natural products, these include: CoQ10, multivitamin and mineral, B complex, vitamin E, vitamin C, garlic, zinc, calcium, flaxseed, and alfalfa. As we can see from this patient's profile she is taking various herbals that could potentially interact with her warfarin therapy. At this patient's first visit her INR was 1.0. An INR of 1.0 is not therapeutic; however, with so many herbals where do you start to try and get a therapeutic INR? It is difficult to get these patient's to discontinue their herbal/natural products because the patient's feel that the products play a vital role in their health. We recommended that this patient discontinue her probiotics to see if that would help her INR reach a therapeutic range. The patient did discontinue the probiotics; however, at the following visit (2 weeks later) her INR still was not therapeutic. As explained above the patient's low INR was not a surprising finding. The extra vitamin K is likely stored in the fat tissue and released slowly back into the blood; therefore, it could take several weeks for us to see any profound effects from the discontinuation of the probiotics. At this visit the patient also mentioned that she felt like she really needed her probiotic because she had been having some digestive problems so she was going to restart the probiotic therapy. Therefore, her

(Continued on page 9)

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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:

Probiotics & Warfarin	1
From the President	2
APSFA Board of Directors	2
A Special Type of Lupus?	3
My Body is a Battlefield	4
Book Review: The Lupus Book	4
Willie's APS Story	5
Breathe Easy	5
Injectable Vitamin K	6
Ten Pains Not to Ignore	7
APS: the Good, the Bad & Ugly	8
Articles Continue	9
FlowerPetal	10

Letter from the President

Spring is here and we will be getting ready for APS Awareness Month in June. It is awesome to realize we will be 6 years old in June.



I would like to thank everyone who donated to decorate our tree! Because of your generous donations, we were able to raise \$1,480.00! The Giving Tree holds a special meaning for the members of the APS Foundation of America, Inc and the community it serves. With it we have been able to get a good start on a research fund. Next, we would like to build a scholarship fund for people who are going into the medical field or are in the medical field. We hope you will support us in this venture.

There have been lots of new products added to our Café Press site. Please bear with us as we get each design updated. Also, you may want to check out our new designs at www.cafepress.com/apsfoundation. Watch for more dragonfly items coming soon.

Speaking of dragonflies, we have made the dragonfly our mascot. Not only are dragonflies pretty but they have such a strong meaning that we found it perfect for APS. A dragon fly is a symbol of sense of self, which comes with maturity. It represents renewal, positive forces and power of life. A pair of mating dragonflies is believed to be a symbol of love. The animal symbolism of a dragonfly is associated with good luck, prosperity, swiftness, strength, peace, purity and harmony. A dragonfly lives a very short life and it tried to live to the fullest with what it has. I think this is the greatest lesson for all of us. We should try to enjoy every single moment of life with what we have.

I do have to say, every time I see someone click that they get their INRs checked via finger stick machines I get nervous for your safety. Please know the manufactures say these machines are not ok for APS patients.

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

Sincerely,

Tina Pohlman

President & Founder

APSFA Board of Directors

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The information in this newsletter is not intended to replace standard doctor-patient visits. All information should be confirmed with your personal doctor. Always see the advice of a trained physician in person before seeking any new treatment regarding your medical diagnosis or condition. Any information received from the APS Foundation of America, Inc. through this newsletter is not intended to diagnose, treat, or cure and is for informational purposes only.

If you have a medical emergency, please call your doctor or 911 immediately.

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A Special Type of Lupus?

Written by: Rosa Sosa

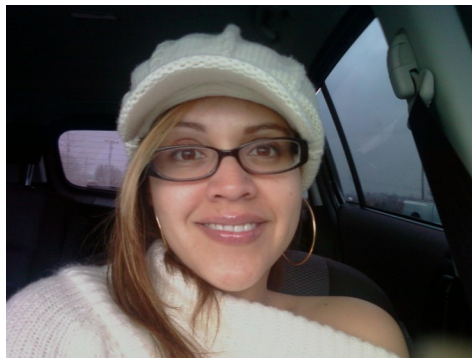
I'm sorry Miss Sosa but we don't understand what is wrong and we are going to have to send you to the John Hopkins Hospital. I lived in Pennsylvania at that time right out of high school and I thought the doctors were talking to me in a different language. What's wrong I wondered? Why do I have to travel so far just to see a doctor? It's just a rash on my leg. What's so hard about diagnosing that? The doctor never gave me an answer he had a really serious look and said "I suggest you leave by this afternoon so you can meet with Dr. Peachtree."

I had no idea what I was in for, so I packed my bag and headed off alone to Baltimore. I don't even remember the drive because my mind was all over the place. I finally got there and gave the reception area my name. In a matter of seconds I was in a wheel chair rushed over to meet with the doctor. She spent a couple of hours running tests and drawing blood. She finally started to examine the rash on my right leg. She looked up at me and said with pity, "Miss Sosa you have a special type of Lupus that I have been studying for two years." Lupus?? Is it curable I began to wonder? I asked about the rash on my leg and she said I had a blood clot behind my right knee that is cutting off the circulation to my foot. They were going to try to remove it. If they were unable to do so we would have a discussion about having a bypass surgery or amputating my foot.

No one in my family had Lupus. I wasn't sure how it found me but it's here to stay. There is no cure for it, just a lot of medication to make you feel a bit more comfortable. Lupus meaning "wolf" is an auto immune disease. The white blood cells in your body fight off infections. When a person has Lupus their white blood cells attack their own

body. Since then I've been in and out of the hospital more than anyone has had a cold.

My family members weren't sure what to make of what was going on. I got the typical, "you don't look sick," "everyone gets tired, maybe you need to eat better and exercise more" or my favorite, "your just getting older you will be fine."



Except neither of those answers proved that my health would get better. I don't think they came to terms with my illness until I suffered a stroke at the age of 23.

There was a point in my life, just as anyone else who has had a life long illness, where I didn't want to believe that this was happening to me. I tried to do everything right in my life, I ate right and exercised and I thought that overall I was a good person. So why did I get such an awful incurable disease. Each doctor that I have seen have only heard about studies on my illness, which is a mouthful Antiphospholipid Syndrome, but have never treated a patient with it.

Time has passed and after 15 years of going through hospitals and a ton of pain, I've realized the saying "Life is what you make of it" to be true. I try my best to inform as many people as I can of this horrific illness that doctors don't look for because it's fairly new disorder in the medical books. I once felt like a freak and now I feel like I have a reason for being in this life.

Many people have heard of cancer and diabetes, especially lately because they are trying to find cures for these unfortunate patients. What people don't realize is undiagnosed this syndrome can kill you. There aren't enough voices

out there and there is definitely not enough funding for a cure. This auto immune disease kills just like any other disease would.

My advice to the world is don't overlook anything that you feel isn't right. Yearly check-ups are important. Don't be afraid to ask your doctor questions, and always get a second opinion. If your doctor diagnoses you with a specific illness look it up on the web and educate yourself about it. Had I stayed in Pennsylvania, I might have died because what was attacking me looked like an innocent rash.

Do Good for Yourself to Do Go for Others

You know that good feeling you get inside when you perform a good deed? It turns out that acts of kindness not only make you feel good, but may actually improve your health and make you live longer. Research suggests that people who do good unto others by volunteering have reduced stress and anxiety, have a greater sense of overall happiness and ultimately live longer than people who do not regularly volunteer.

The good news for everyone is that we can all reap the physical and psychological benefits of kindness even without spending lots of money or time. Not sure where to start? Check out "The Random Acts of Kindness Foundation" at actsofkindness.org for hundreds of ideas for kindness geared toward individuals, schools, communities, faith groups, children, families and more.

The next time you're upset, consider writing a nice note to your server on the back of your dinner bill, giving a hug to a friend, paying for the coffee of the person behind you in the drive-through or putting a flower on your neighbor's porch. It's hard to stay upset when you're doing good for others.



My Body is a Battlefield

Written by: David Deicher

I was riding my motorcycle one day to work when I noticed that I had issues seeing out of my right eye. Half of my vision in that eye was just grey while the upper half was clear as the blue sky that day. I didn't think much of the situation until it happened a second time which at that point I called my ophthalmologist and made an appointment.

When I met the eye doctor, I was told that the vision "issue" was just migraines. Somehow deep inside I didn't quite believe it and it was a good thing that I didn't.

I ended up getting a second opinion with my regular physician who immediately sent me to a Neurosurgeon and within several days I was having my first carotid surgery. My right carotid was over 90% blocked. I was only 37 years old. While my family and I made it through the surgery and everything went fine, we thought that this chapter of my life was over. To find out that this was just the beginning.

At the age of 42, I had the same issue with my eye. My wife immediately took me into the emergency room and 2 days later I had a stent placed in my right carotid artery. The same one they cleaned out just 5 years earlier. While recovering from surgery, I was told the news that I had APS. My family and my life changed forever but we made it through another surgery and started looking towards the future once again.

Just 8 months later, I had a massive heart attack caused by having two clots enter one of my main arteries. My wife got a call at work telling her that I collapsed at work and was not breathing and to be prepared that I may not be alive by the time she got to the hospital. Through excellent and quick thinking from co-workers doing CPR and using a defibrillator - to the excellent doctors and special treatment - I made it to the hospital. After being in a coma for 5 long days, I opened my eyes and saw my wife and my family standing there. Once again, I was told that the APS had taken control of my body.

Yet just under 2 years later, I was back in the hospital getting ready for my left carotid to have surgery as the APS had clogged yet another major artery. Once again, I went through the surgery. December, I went in for my routine check up of my carotid and got great news, they both were staying clear! I remember thinking 2010 will be a good year, no surgeries, no symptoms, my INR was in good shape, and my APS seemed to be under control.

In May, we had our first real vacation that wasn't medical leave for the first time in years, and we flew off to Greece. We got the clear from the doctors that it was okay to go and that I was doing well. I was so happy for

the first time in a long time. Two weeks after we got back, I went in for yet another routine check up and two days later I was told I was scheduled for surgery for my right carotid



once again. This time angioplasty with a possibility of another stent under the stent they put in almost 10 years ago. We were devastated. The doctors were lucky enough that they could just do the angioplasty but I was told after the surgery that my left side carotid was almost 50% blocked. The artery that I just had cleaned

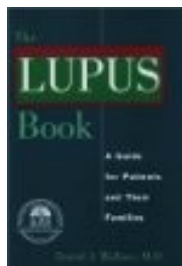
out almost to the year of this surgery.

I have made it through all of this with the help of my family and friends but most of all because of the doctors that take APS seriously. I struggle sometimes not knowing if this is going to be a death sentence for me. I ask myself - is this terrible disease going to cause my wife to be a widow or is my mother going to lose a child? It is almost overwhelming at times. But I remember, I have gone through all of this and I am still here. I think to myself "I died and I am still here." I take every opportunity that the hospital asks of me to partake in any research for this disease believing that some day there will be decent treatment and maybe even a cure.

Everyday is a struggle for me and my family

Book Review: The Lupus Book

Written by: Denise Orin OTR, CHT



The Lupus Book: A Guide for Patients and Their Families by Dr. Daniel Wallace; Published in 2000 by Oxford University Press; Rev & Expand edition; ISBN: 0195132815

As I was in process of being diagnosed, I went to our local public library to have a greater understanding of what I was dealing with. I came across an older edition of this book and bought the new one as a reference for myself. Even though I do not have Lupus, but do have APS it helped me to understand what the doctors were looking at and what tests I needed to have done and why.

Chapter 21 asks the question "Why do blood clots develop?"

Throughout this 6-page chapter Dr. Daniel Wallace MD, the books author, talks about the essential tests performed and why they are done. He mentions several statistics that are basic in nature but give the reader a reference for where they may fall in the spectrum of patients with this problem.

He asks the question "How Should Antiphospholipid Antibodies be treated?" In his own answer he gives brief mention to management of our condition thru several medications citing the ones most of us have heard of and the relative doses used for symptom control.

He clearly notes, "Few dietary or activity restrictions can aid prevention".



Willie's APS Story

Written by: Willie Ruona

Hi, my name is Willie Ruona and this is my story.

In November of 2007, I was 45 years old. My wife and I were semi-retired, living in our RV in south Texas and working as gate guards in the oilfield. We were having a great time and had no stress.

I woke up one morning and my left leg was sore and swollen. I figured I had pulled a muscle and kept on. The swelling got worse until my thigh was twice the size of the other leg. I was reluctant to go to the doctor as we had no insurance but after a couple of weeks I couldn't take it anymore. I went to the local clinic and they did an ultrasound and discovered the clot.

As my wife and I were both EMTs, I knew how serious a DVT could be. I was taken to the hospital where I stayed for a week while they stabilized the clot. I was put on warfarin. After 6 months I was told I could discontinue the warfarin.

A day or two before Christmas, 2008, I began to feel that familiar pain and swelling.

On Christmas Eve, I went to the hospital and they again found a series of clots in my left thigh. I was discharged a week later and again put on warfarin.

I was told that being overweight, smoking and sedentary lifestyle led to my clot.

I was again taken off the warfarin. I then got a job as a carpenter and be-

came very active and joined a softball team.

Even with these changes (I admit I kept smoking) I got another clot in March of 2010.



This time it was in my right thigh. I was told it was a series of clots stretching from groin to knee and the vein was almost completely occluded.

I was again discharged and put on warfarin.

In May, I started getting pain in my left wrist. I told my wife it felt like a bone spur. Within a month, all my joints were causing me excruciating pain. My doctor took an ANA test and concluded I had an autoimmune disease and sent me to a rheumatologist.

Within four months, I could no longer work due to the pain, fatigue and extreme joint weakness.

I was fortunate in that one of the world's leading rheumatologists is in my city. She was able to diagnose me as having APS secondary to polyarthropathy by January of 2011.

I feel fortunate that I have not struggled with misdiagnosis and unknowledgeable doctors for years as so many have.

I currently suffer from joint pain, fatigue and headaches. I know my life will never be the same as it was but I am confident that my doctor and I can devise a treatment regime to get my life back on track.

Breathe Easy

Submitted by: Heidi Ponagai

What do you do about 20,000 times a day, can be done anywhere, is absolutely free and can increase your well being? Breathe. Mindful breathing is healthy, relaxing and beneficial. By learning to pay attention to your breathing and controlling it better you can lower blood pressure, heal faster and possibly increase immunity.

Here's how it works. As you inhale through your nose or mouth, the muscles between the ribs expand and the diaphragm moves down. Your lungs fill with oxygen which then moves into the bloodstream and helps cells produce energy. As you exhale, carbon dioxide is released which is a toxin. So the saying goes, "in with the good, out with the bad."

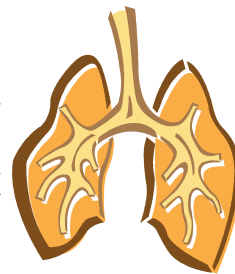
You may not realize it but your breathing changes depending on how you feel. When you feel calm, your breathing slows, blood pressure lowers and heart rate drops. This is the relaxation response. When you are anxious your body releases adrenaline and cortisol which increases your blood pressure and heart rate, causing breaths to be quick and shallow. This is a stress response.

Try to inhale filling up your lungs and allowing your abdomen to expand, and then exhale smoothly. Two or three deep breaths can be very calming. Even a deep breath at regular times during the day will break up and decrease your stress response. Take a deep breath before answering the phone, before you get out of the car or before an important meeting or conversation.

This will help you relax and focus.

If you have trouble falling asleep or need to quiet your mind try counting one as you inhale, two as you exhale up to

ten. Or, try breathing in a positive word or soothing color and exhale a negative one.

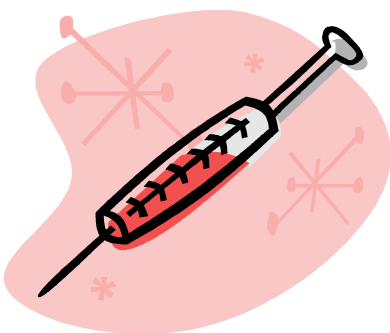




There Is No Good Reason to Carry Injectable Vitamin K at All Times

Written by: Al Lodwick, RPh, CACP

I would like to start by stating my personal bias. For most of his adult life, my father had a clotting disorder resulting in many hospitalizations. It was probably APS but never diagnosed. He died of a massive pulmonary embolism a few days after a physician stopped his warfarin to perform a relatively minor procedure. Therefore, I am quite intolerant of people having low INRs. I believe that almost any bleed is preferable to almost any clot.



Carrying a vial of vitamin K injection at all times to treat an elevated INR seems like a good idea at first, but when you consider how vitamin K works, you will see why there is no good reason to do this. The most obvious reason is that it is inconvenient to carry a glass container and a syringe. That being said let's turn to the science behind the use of vitamin K

Vitamin K has absolutely no effect on the clotting factors circulating in your blood. (Having an excess of these clotting factors is what causes the International Normalized Ratio [INR] to be too high.) Vitamin K slows the production of these clotting factors. To use an analogy of driving a car, we imagine that vitamin K is like stepping on the brakes. Because of all the steps involved in slowing the production of clotting factors, vitamin K could be more properly thought of as turning off the key and letting the car roll to a stop every time you needed to stop. Giving a large overdose of vitamin K (10mg IV) will reverse the INR a little quicker. This could be likened to not only turning off the car's motor, but also pulling a plug to

drain the gas out of the tank. You can see how this is not a very effective way to stop a car. Likewise, vitamin K is not a very efficient way to reverse an elevated INR. Because of the long series of steps to slow the production of clotting factors a shot of vitamin K works only slightly faster than swallowing a pill.

When a large overdose of vitamin K is given it is quite possible that a person is at a higher risk of clotting for maybe two weeks. This has not been proven because doing a study where people would be given enough warfarin to elevate the INR and then a massive dose of vitamin K would be unethical to say the least. My philosophy when dosing patients was that I would rather that someone had a bleed than have a clot. The vast majority of bleeds occur in the nose or gut. Brain bleeds are fairly rare. Clots tend to occur in the legs (where they can go to the lungs) or in the brain. To my way of thinking it is easier to get blood from a blood bank than it is to get a replacement lung or brain.

Another reason to not carry shots of vitamin K is that giving them to someone who is not bleeding is simply treating a laboratory value, not an actual condition. By injecting vitamin K for an elevated INR with no bleeding you are only trading the risk of bleeding for the risk of clotting. If you are having serious bleeding, then you need to be treated with more efficient medications that directly inhibit the clotting factors circulating in the blood rather than vitamin K.

Other arguments against the use of vitamin K shots are based on what

happens after the shot is given. There are many reports of skin reactions caused by vitamin K shots. A shot of vitamin K given just below the skin (like insulin is given) may not be well absorbed by the body. So you will have to wait a day or so to see if it worked. A deeper injection into a muscle carries a risk of causing a nasty type of bruise called a hematoma. This can easily become infected. An injection of vitamin K directly into the vein carries a very slight risk of a life-threatening reaction, similar to a severe allergy. So there is no excellent route of giving vitamin K by shots.

Merely holding warfarin doses for INRs between 5 and 8 when there is no bleeding has been shown to be safe and effective.

In my opinion, it is not a good idea to carry vitamin K for routine use by shots. If you have an elevated INR with no bleeding or only have a minor bleed then no treatment is necessary. If you have a serious bleed then you need a faster acting treatment than vitamin K. If you feel the need to carry a "lucky charm" consider one 5mg vitamin K tablet. This will work almost as fast as a shot with much less risk of doing harm.

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Ten Pains Not to Ignore

Written by: Tina Pohlman

Nearly everyone suffers from aches and pains at some point. While it's tempting to put on a brave face and carry on, it's important to remember that pain is an important warning sign, letting you know when something is wrong with your body. While most pain – scrapes and bruises, mild headaches or muscle aches, stomach upsets – probably isn't serious enough to require medical attention, there are certain cases when it's better to be safe than sorry. The following types of pain should never be ignored.

Worst Headache Ever. If you're having the worst headache you've had, seek medical care immediately. It might be due to a bad migraine or a sinus infection that needs treatment. But if it's causing pain unlike anything you've ever experienced, it could be something more serious like a ruptured brain aneurysm (a bulge or ballooning in a blood vessel in the brain) or a brain tumor. A ruptured aneurysm can create dangerous bleeding in the brain, sometimes resulting in death, so it's important to seek treatment at the first sign of symptoms.

An Aching Leg. Sudden and unexplained pain in the calf muscle may be a symptom of deep vein thrombosis (DVT). DVT is a life-threatening condition in which a blood clot forms in a vein deep inside the body, usually in the legs. A clot can block blood flow and, if left untreated, it can break away and travel through the bloodstream to the heart, lungs or brain causing severe damage and possible even death.

DVT occurs in about 2 million Americans every year. It can develop from spending too much time sitting in one position, such as during a long plane ride, from prolonged bed rest, or if you have a health problem that affects how your blood clots.

Elastic stockings, which are available at most local pharmacies, may be useful in preventing DVT, so you may want to discuss this option with your healthcare provider.

Unexplained Pain with Rash. An unexplained and uncomfortable itching, tingling or burning sensation followed by the development of a rash and mild to severe pain may be shingles. Shingles can be a painful and debilitating condition caused by the same virus as chickenpox. After you have chickenpox, the virus remains inactive in your body in certain nerves. If the virus becomes active again it causes shingles.

The concern is that the shingles virus can cause nerve

damage potentially leading to the development of severe, long term pain known as Post Herpetic Neuralgia Pain (PHN). PHN affects the nerves and skin in the area where the shingles outbreak occurred. Early treatment of shingles can greatly reduce your chance of developing PHN, so be sure to see your healthcare provider at the first sign of symptoms.

Almost one out of three people in America will develop shingles during their lifetime, with greater risk to older adults. The Centers for Disease Control and Prevention says that the only way to reduce the risk of developing shingles and the long term pain that can follow is to get vaccinated, and highly recommends vaccination for adults ages 60 and older.

Pain or Discomfort in the Chest or Upper Body. Pain or discomfort in the center of the chest can be a key warning sign of a heart attack. It can feel like uncomfortable pressure, squeezing or fullness, and usually lasts for more than a few minutes, or it may go away and come back.

“Pain or discomfort in the center of the chest can be a key warning sign of a heart attack. It can feel like uncomfortable pressure, squeezing or fullness, and usually lasts for more than a few minutes, or it may go away and come back.”

The pain and discomfort associated with heart attack may also be felt radiating to the back, jaw, throat, or left shoulder or arm. Heart disease is the leading cause of death in America, and symptoms differ for men and women, so talk with your doctor about your personal risk.

Severe Abdominal Pain. If you still have your appendix and you suddenly begin to experience severe abdominal pain, seek immediate medical attention. While it may be something minor like gas or indigestion, it's better to be overly cautious than to risk the possibility of rupture.

Appendicitis pain typically begins around the navel and then shifts to the lower right abdomen. However, the location and severity of pain may be slightly different for everyone based on factors like age and the position of the appendix. Any severe abdominal pain should raise a red flag, not just pain on the right side.

Other abdominal conditions that may require prompt treatment include stomach ulcers, intestinal blockages, problems with the gallbladder or pancreas, and several types of infection.

Changes in Chronic Pain. Sudden changes in the severity of chronic pain that are accompanied by a loss of sensation and / or weakness may signal the need for immediate



APS: the Good, the Bad and the Ugly

Written by: Michelle Klemm



He did an extensive blood panel and called me to tell me I had APS and needed to be seen by a hematologist. Of course, I was like “I have what?” and so began my journey.

Because my clotting episode was in the colon I cannot take prescription blood thinners because the thought process is the next clot has a higher probability of being there

different thing I have going on. I am still hopeful for advances to help treat all of us who are coping with APS.

In closing, APS: The Good—APS has given me a new appreciation for life and the things that are really important. It’s taught me that there’s no time like the present to say “I love you” or “I’m sorry”. APS: The Bad – I have constant monitoring which means lots of visits to different doctors and due to the meds lots of blood work but at least I have a good medical team who is keeping close watch on me. APS: The Ugly – I have this “new” body that I’m still trying to adjust to. Stopping of hormone replacement therapy and almost all the meds I take causes weight gain so there’s more of me to love now!

Someone dear to me reminded me that I’m more than a pant size and she was right! I am a wife, mother, grandmother, daughter, sister and friend who will continue to educate myself on this illness and contribute in whatever way I can to reach a cure.

In June of 2009, I was busy going about my life. My husband and I had just opened our own business so there were lots of changes going on in our lives. I became very ill with what I thought was a nasty stomach virus however this virus was “different”.

I couldn’t eat or drink anything and the pain was excruciating to say the least. I couldn’t walk without bending over and holding my stomach and I couldn’t even stand for my husband to turn over in bed so I knew something was going on.

I went in to see my family doctor and they could tell right away this wasn’t anything “normal”. They immediately sent me to a gastroenterologist the next day. The nurse practitioner came in and did the exam and quickly found lots of blood evidence. She immediately called the gastroenterologist and they set me up for a colonoscopy the next morning.

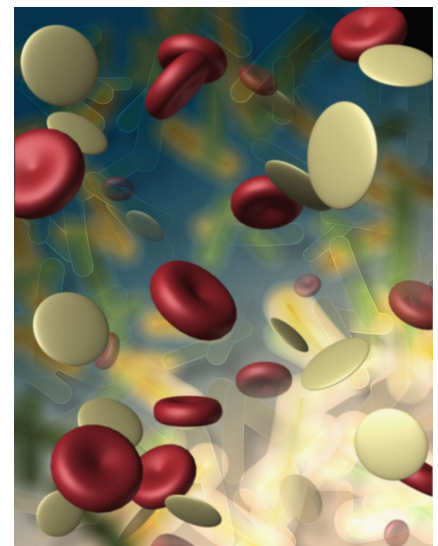
When in recovery the doctor came in and told me that I had a blood clot in my colon. He explained to me that this was not normal and that he wouldn’t stop until they found out what was wrong. He immediately stopped the hormone replacement therapy I had been on for 11 years. Talk about a rude awakening!

than anywhere else and according to the doctors if that happened I would bleed out before anyone could help me. So, I take a full strength aspirin daily. So far no other clots however my body began to fail me in a terrible way. I am in so much pain in my joints on the right side of my body and my tendons. One of my other doctors is a rheumatologist and he has been puzzled.

I am told that other auto-immune diseases that go along with APS are typically soft tissue in nature so the first place they started looking was for Lupus. That test was fine. The pain progressed and my right hip was hurting so bad that I could barely walk. An MRI revealed the big tendon that attaches to my hip was torn. How? That was my question. I don’t work out (shame on me) and I had not had an accident.

Following this came plantar fasciitis in the right foot. After more history the rheumatologist finally got it – it was psoriatic arthritis. They were looking for an elephant when there was a giraffe on the loose.

I am still waiting for the perfect drug combo to help with the pain I’m in 24/7. I am still trying to get my friends and family to understand this very





(Continued from page 7)

attention. Your healthcare provider can help determine whether or not your condition has worsened or calls for a new course of treatment. Painful flare ups can often be managed by adjusting your current medication or therapy, so don't feel as though you have to suffer through worsening pain.

Pain Following Surgery.

Chronic pain can develop after surgery if postoperative pain is not appropriately assessed and managed. While researchers aren't exactly sure why this happens, evidence shows that effective pain management immediately after surgery may lead to less pain later on. If you are going in for surgery, please speak with your doctor and / or the anesthesia provider in advance to develop a pain control plan following your procedure. If you've recently had



surgery and don't feel like your pain is being managed well, contact your healthcare provider right away.

Pain That Wakes You Up at Night.

It's normal with certain injuries and conditions to go to bed in pain and wake up the next morning still in pain. But if you have pain in any part of the body that is so severe it wakes you up from a deep sleep, make an appointment to see your healthcare provider immediately. This could be a sign that

something serious is wrong, or that your current pain needs to be managed more effectively.

Dental Pain. Any pain or injury to the teeth or gums can be potentially serious. Dental problems can lead to permanent damage, and delaying care can mean costlier treatments later on. Even an injury that seems small can have the potential to damage tissue, nerves or blood vessels, or lead to a life threatening infection. Most dentists

reserve time in their day for possible emergencies, so there's no need to wait.

Tingling or Pain in Your Legs or Arms.

It could be peripheral neuropathy, a term for damage to nerves of the peripheral nervous system, which transmits information from the brain and spinal cord to every other part of the body. Peripheral nerves also send sensory information back to the brain and spinal cord, such as a message that the feet are cold or a finger is burned.

Symptoms may include temporary (or in some cases ongoing) numbness, tingling, burning, coldness or weakness in the arms or legs. This could signal diabetes, certain vitamin deficiencies, repetitive stress, autoimmune disorders, among other problems.

Sources:

Mayo Clinic, American Heart Association, National Lung & Blood Institute, American Dental Association, Air Transport Users Council

(Continued from page 1)

warfarin dose was increased about 20% and she will have her INR tested every 7-10 days.

Conclusion: Probiotics are usually taken to help improve the body's natural intestinal bacteria. Probiotics can potentially interfere with warfarin therapy because probiotics produce vitamin K that is used by the body to produce clotting factors. A person who is taking probiotics may need to have their warfarin dose adjusted in order to reach a therapeutic INR. This is just one example of a patient who was taking probiotics while on warfarin. From this example you can see that the patient was taking several herbal/products that could interact with her warfarin. In addition, it is difficult to get



these patients to discontinue their herbal products.

One last thing to think about is that dietary supplements such as probiotics have little regulation in the United States. The FDA requires that the manufacturers list the ingredients but the manufacturers do not have to prove that the product is safe and efficacious like other drugs. Lastly, even though the manufacturer must list the ingredients on the package the FDA does not perform any type of

chemical analysis to verify what is listed on the package; therefore, you really don't even know what you are buying.

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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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