ANTIPHOSPHO...WHAT?

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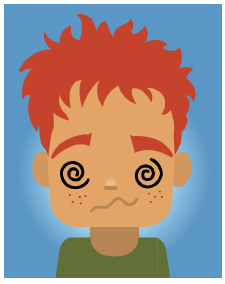
The APS Foundation of America, Inc. Board of Directors would like to wish all of our volunteers, donors, friends, forum participants & those individuals who have contributed to the success of this Foundation

A Joyous Holiday Season!

Vertigo/Dizziness & APS: How are they Connected?

Written by: Flavia Fleming and Roger A Levy
Otorhinolaryngology and Rheumatology
Universidade do Estado do Rio de Janeiro, Rio de Janeiro, Brasil.

Some has been said about the association of otological problems with APS. But if you look out for scientific reports in this area, very little information is available.



Researchers have described that a wide spectrum of symptoms are often seen in APS patients, and these symptoms can usually be said to look a lot like Meniere's Syndrome.

The four predominant symptoms of Meniere's syndrome are vertigo, hearing loss, aural fullness and tinnitus. The vertigo usually lasts more than 20 minutes, commonly several hours, but also can last some days, and frequently comes along with the other symptoms.

We know that in this syndrome there is an elevated pressure inside the endolymphatic system (active and sensible part of the inner ear), but the basic cause is still speculated. We also know that the blood flow system working in the inner ear (cochlea and posterior labyrinth) is a key element for the perfect operation of the extremely sensible sensors in these structures. So consistent theoretical explanations for Meniere's in APS patients is that not only the thrombotic manifestations, but also the autoimmune and inflammatory alterations can lead to an insufficient circulation in this area, with malfunction.

Another symptom commonly seen in APS patients is isolated, fluctuating and progressive hearing loss. We have particularly seen a close relationship of the otological symptoms and the poorly controlled INR (when it is below the therapeutic range). Also, the use of low molecular weight heparin seems to be more effective than the use of warfarin in these cases.

As many scientists have already described, heparin has not only the anticoagulant property but also an anti-inflammatory effect. When we consider all the possible vascular alterations present in APS, we can never forget that vertigo and dizziness can also be symptoms from central nervous system etiology, such as strokes and TIAs (transient ischemic attacks).

A lot is still to be discovered about the pathophysiology of all these alterations, and the best ways to treat them.

For more information please see this article: The Laryngoscope, Lippincott Williams & Wilkins, Inc., © 2005 The American Laryngological, Rhinological and Otological Society, Inc. Antiphospholipid Inner Ear Syndrome, Debbie Aviva Mouadeb, MD; Michael J. Ruckenstein, MD

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Patient Stories & Articles Needed!

We are always 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.

If you have sent your story and haven't heard back from us, please contact us again.

Without your help our newsletter cannot be a success!

Inside this issue:

Letter from the President

Winter is upon us hard and heavy. Although much of the country in not in this bitter cold, personally me and my cats (heck even my car) are ready for summer again.

I am pleased to announce that the APSFA has helping a lot with APS ACTION and have helped apply for a grant with Dr. Ortel. As you may already know Silvia Pierangeli, PhD, one of our wonderful medical advisors, passed away a few months ago. She will be greatly missed. We will be donating 50% raised on this year's Giving Tree in memory of Silvia to APS ACTION. This will help us ALL. They are doing a lot of new research. We are proud to be one of their sponsors.

We were represented at the 14th International Congress in Rio but haven't received the report yet. The next Congress will be in Turkey and will be doing what we can remotely like we did for Rio. Hopefully we will have a late report on Rio for the next newsletter.

We are also pleased to announce there has been a greater demand for our services and information packets. We are in need of donations to get items printed and postage paid for as we realize many of our clients are unemployed, low income or disabled and cannot afford to make a donation to get this information to them. With our generous donors help, we have been able to provide these services & information free of charge and hope to continue to do so.

Please note that we do have hours. They are from 11AM CT to 3PM CT. Tuesday - Friday unless I have a doctor's appointment. Calls will be returned as soon as possible. Also, please do not call the office line after 5PM CT as it rings directly into my house with no way to let it go directly into voice mail. We initially set it up this way to reduce cost. However, recently, I have been getting many middle of the night calls. Please be mindful of the time when calling us. If the late night calls continue, then we will be forced to get a business line. Personally, I would rather see donations be used another way than a dedicated phone line.

Also, please understand I have been very sick lately due to Lupus and has been pretty much in bed for the last several months. I am trying my hardest to keep on top of everything by my health has to come first. So, please bear with me.

Remember to sign up for the e-Newsletter at http://tinyurl.com/3rvb379 . We are planning on sending special articles out that will only be available to those that are on our email list.

Once again, I hope this newsletter finds you in the best of health and with a perfect INR level. I wish you the Happiest of Holiday's and a Very Healthy New Year.

Sincerely,

Tina Pohlman

President & Founder

APSFA Board of Directors

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Silvia Pierangeli, PhD (1955-2013)

Written by: E. Nigel Harris, MPhil, MD, DM
Professor of Medicine
Vice Chancellor, The University of the West Indies, Jamaica

In September 2013, the world lost one of the most prolific researchers in the field of anti-phospholipid(aPL) antibodies and the Anti-Phospholipid Syndrome -- Dr. Silvia Pierangeli. Over a period of 25 years, she with a variety of co-workers built a prodigious record of published work encompassing research in several areas related to this field that included: development of more reliable testing for anti-cardiolipin antibodies; creation of a mouse model to determine how aPL antibodies might cause thrombosis; utilization of mice, to explore pathways by which these antibodies might be induced and this way possibly providing an explanation for causation of APS; investigation of a variety of treatment options utilising mouse models and translating these findings to studies in patients; and, finally, she helped develop an alternative test, the APhL ELISA, that might more reliably diagnose the disorder.

Dr. Pierangeli was born in Argentina and was educated at Buenos Aires National University, where she obtained a PhD degree. Her parents, Dr. Hector and Mrs. Suzanna Pierangeli owned a private laboratory and Silvia started acquiring her diagnostic testing skills from an early age. In 1986, Dr. Pierangeli won a Fulbright Scholarship and moved to Louisville, Kentucky to study for a second PhD degree at the University of Louisville. It was there that she united with this author (ENH), first as post-doctoral student but then as a full-fledged colleague. Over the next twenty years, Silvia advanced to become a full-fledged independent investigator attaining the rank of full professor at Morehouse School of Medicine in Atlanta, then at the University of Texas in Galveston.

While Silvia developed an exceptional record as a researcher, it is her people skills for which she will be most remembered. She combined warmth, generosity, energy, a love of life lived to the fullest, caring for people and patients with whom she interacted – (it was difficult to remember that she was not a medical doctor) – and an openness to new ideas and alternate points of view. She had a passion for her work best manifest in a refusal to take "no" for an answer and a determination to win over her worst critics and detractors – an important attribute in the world of science. These attributes and skills endeared her to collaborators around the world, who admired both her work ethic and personal qualities.

Silvia's passing occurred all too suddenly – within 6 weeks of a diagnosis of pancreatic cancer-- but her legacy both in terms of her work and personal warmth will live on. She is survived by her daughters, Cecilia and Eugenia and her husband, Alvaro Schleh.

A note from the APSFA:

Dr. Pierangeli was a member of the APS Foundation of America, Inc's Medical Advisory team. We have been in contact with and worked with her for a couple years.

She was always helpful and supportive, offering advice when requested. Her knowledge and kind nature will definitely be missed.

The APSFA will be sending 50% of our Giving Tree donations to APS ACTION to honor Dr. Pierangeli's memory, as an APS researcher, advocate, and friend.

APS ACTION is a network of internationally renown physicians and scientists that works to find a cure for Antiphospholipid Syndrome.

If you would like to make a donation to our Giving Tree this December, please our website:

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

Different Ways To Donate To The APSFA This Coming Holiday Season

Written by: Heidi Ponagai

The 2013 Holiday season is upon us and not unlike most years, it seemed to sneak up on us so quickly! The time has come 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. Thank you for your consideration.

Donation Ideas

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

- We always accept monetary 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 through US mail and credit card donations through PayPal.
- On our website we have APS informational booklets, burgundy ribbon, infant loss, and APSFA lapel pins, postcards, APSFA pens, and new APS Awareness bracelets 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.
- Our Flowerpetal site is open year round. 12% of all sales goes to the APSFA and shipping is always free!
- You can also do your online shopping through our Amazon link or using GoodShop.
- In our CafePress store we have many holiday items: cards, ornaments, stockings, etc, as well as a large variety or unique APS & Lupus awareness items.

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 2013 post dated by 12/31/13.

APSFA 8th Annual Online Giving Tree

Our annual "Giving Tree" has been planted for the 2013 season and its bare branches are eagerly waiting your ornament donations!

The "Giving Tree" works the same as past years: each ornament on and package under the tree represents a generous donation. All "Giving Tree" donations are tax deductible.

There are PayPal buttons for making special "Giving Tree" ornament donations on the site under the tree. Ornaments are available in different shapes and colors to represent different donation denominations, and just like last year, all donor names will be printed underneath the tree and the ornaments will be added to the tree.

Ornaments can also be donated in memory or in honor of someone.

By the end of the season our tree is beautifully decorated by the generosity of our wonderful donors!!

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

As has been our tradition since 2005, our exclusive APSFA Keepsake ornament is available in our CafePress online store. The ornaments are $8.99 each and are made of porcelain.

We have chose a snowflake to adorn our ornaments because all snowflakes are different, just like every APS patient is different.

This exclusive design is also available on other items in the store.

We have a wide selection of APSFA, APS, DVT, Lupus, Infant Loss, FVL, and thrombosis awareness gear located on our CafePress online store. With everything from t-shirts to car magnets, you will be sure to find the perfect gift!

With every item purchased, the APSFA receives a small donation. Thank you to everyone who's purchased our items!

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.

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

What's Happening To Our Family?

Four sisters try to deal with the sudden loss of their youngest, and only, brother Brian

Written by: Gloria Schaefer

He was a gentle giant, always happy. He loved to work on cars, especially Ford Torino's. Brian was only 27 when he died. As far as we know he was healthy and had passed a yearly work-physical a few months earlier. He loved to show off his baby daughter, Kayla, to the neighbors.

My name is Gloria. I am a registered nurse in outpatient surgery and mother of three children, Kelly, Rob and David. I have three married sisters, Phyllis, Denise and Valerie.

I will always remember the day we got the call. It was a beautiful October morning in 1990 and the leaves were all orange and yellow. I remember telling my husband Bob that I actually was thanking God for the beauty of fall as I drove home. Then the phone rang and I heard my sister-in-law Denise, in a panicky voice, cry out - "I just came home and found Brian, I think he's dead". I asked her if she called 911. She said yes but she couldn't get him off the chair to do CPR. Brian was six foot four inches tall and weighed 250 pounds. Denise was 4 foot and weighed 110 pounds. She said he had been holding Kayla, their three-month-old baby, who had rolled onto his feet and was crying. I told Denise we were on the way and my husband Bob and I headed to their apartment.

When we arrived there were emergency vehicles everywhere. My husband let me out of the car while he found a place to park. I ran up the stairs and into the apartment to see if they had revived Brian. A man in street clothes grabbed me and pushed me into the wall just as Bob came running up the steps and said to him "get your hands off my wife". The man let go of me and

Front left to right: Denise, Gloria, Eleanor, Brian. Rear: Valerie, Phyllis.

told us to wait in the neighbor's apartment with Denise. He was a detective and they were treating my brother's death as a murder. There was not an ounce of compassion shown to Denise or myself. I've always felt (unrealistically) that I could have breathed life into Brian and helped him to live. Only a month before Brian's death we sisters were sitting in Baker's Square marveling how fortunate our family had been, to never have had any broken bones or serious injuries or accidents.

Because of his age and the fact that he was healthy, Brian was a coroner's case. The autopsy revealed that Brian's coronary arteries were clear, but the small vessels in his heart were clotted and that he most likely went into vfib or vtach as the cause of death. What happened to Brian? None of us had ever heard of antiphospholipid syndrome (APS) or been diagnosed with it yet. And so began the worst two years of our lives. The grief was unbelievable, especially for my mom; our dad had died five years earlier at age 65 from a ruptured aortic aneurysm.

My sister Phyllis and I cried so much we awoke with wet pillowcases from crying in our sleep. Only people who have lost someone they love deeply can understand this type of grief felt by mom and all of us sisters. "Why Brian, and why so young"?

A year after Brian died, my mother started having difficulty walking. She was wrongly diagnosed with an acute osteoarthritis flare-up and placed on high dose steroids. She became confused and was unable to walk. I took her to the emergency room again and asked if it was possible she had deep-vein thrombosis (DVT's). The ER doctor said it could not be DVT's because it was occurring in both legs. He was going to send her home and treat her for a bladder infection. I disagreed and refused to take mom home. I explained to the doctor that two weeks prior mom was driving her car and now she couldn't even walk. The doctor relinquished and had mom transferred to Metro General Hospital in Cleveland, Ohio for further diagnosis. Within an hour of admission at Metro General, doctors ordered a venous scan of both legs and found mom had multiple DVT's. She spent the whole summer on a heparin-drip and had to learn to walk again. She was also steroid-toxic from high doses of prednisone.

Fast-forward another year. I am 44 now and starting into menopause with hot flashes. My gynecologist suggests hormone replacement therapy (HRT). I agree-all the literature suggests it will

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Beat the Winter Blues
Shedding Light on Seasonal Sadness

Submitted by: Todd Ponagai

As the days get shorter, many people find themselves feeling sad. You might feel blue around the winter holidays, or get into a slump after the fun and festivities have ended. Some people have more serious mood changes year after year, lasting throughout the fall and winter when there's less natural sunlight. What is it about the darkening days that can leave us down in the dumps? And what can we do about it?

NIH-funded researchers have been studying the "winter blues" and a more severe type of depression called seasonal affective disorder, or SAD, for more than 3 decades. They've learned about possible causes and found treatments that seem to help most people. Still, much remains unknown about these winter-related shifts in mood.

"Winter blues is a general term, not a medical diagnosis. It's fairly common, and it's more mild than serious. It usually clears up on its own in a fairly short amount of time," says Dr. Matthew Rudorfer, a mental health expert at NIH. The so-called winter blues are often linked to something specific, such as stressful holidays or reminders of absent loved ones.

"Seasonal affective disorder, though, is different. It's a well-defined clinical diagnosis that's related to the shortening of daylight hours," says Rudorfer. "It interferes with daily functioning over a significant period of time." A key feature of SAD is that it follows a regular pattern. It appears each year as the seasons change, and it goes away several months later, usually during spring and summer.

SAD is more common in northern than in southern parts of the United States, where winter days last longer. "In Florida only about 1% of the population is likely to suffer from SAD. But in the northernmost parts of the U.S, about 10% of people in Alaska may be affected," says Rudorfer.

As with other forms of depression, SAD can lead to a gloomy outlook and make people feel hopeless, worthless and irritable. They may lose interest in activities they used to enjoy, such as hobbies and spending time with friends.

"Some people say that SAD can look like a kind of hibernation," says Rudorfer. "People with SAD tend to be withdrawn, have low energy, oversleep and put on weight. They might crave carbohydrates," such as cakes, candies and cookies. Without treatment, these symptoms generally last until the days start getting longer.

Shorter days seem to be a main trigger for SAD. Reduced sunlight in fall and winter can disrupt your body's internal clock, or circadian rhythm. This 24-hour "master clock" responds to cues in your surroundings, especially light and darkness. During the day, your brain sends signals to other parts of the body to help keep you awake and ready for action. At night, a tiny gland in the brain produces a chemical called melatonin, which helps you sleep. Shortened daylight hours in winter can alter this natural rhythm and lead to SAD in certain people.

NIH researchers first recognized the link between light and seasonal depression back in the early 1980s. These scientists pioneered the use of light therapy, which has since become a standard treatment for SAD. "Light therapy is meant to replace the missing daylight hours with an artificial substitute," says Rudorfer.

In light therapy, patients generally sit in front of a light box every morning for 30 minutes or more, depending on the doctor's recommendation. The box shines light much brighter than ordinary indoor lighting.

Studies have shown that light therapy relieves SAD symptoms for as much as 70% of patients after a few weeks of treatment. Some improvement can be detected even sooner. "Our research has found that patients report an improvement in depression scores after even the first administration of light," says Dr. Teodor Postolache, who treats anxiety and mood disorders at the University of Maryland School of Medicine. "Still, a sizable proportion of patients improve but do not fully respond to light treatment alone."

Once started, light therapy should continue every day well into spring. "Sitting 30 minutes or more in front of a light box every day can put a strain on some schedules," says Postolache. So some people tend to stop using the light box-

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In One Day Everything Changed

Written by: Gabrielle Byrnes

I was only 16 when it really started. I was in high school, a somewhat typical teenager with my eyes on the bright lights ahead, thinking of what I wanted in life. My days consisted of reading, writing, photography, being with the few dear friends I had, and of horseback riding. I had been riding for 11 years and it was just as much a part of me as my skin.

But, that was when everything changed. I started getting sick. Every month I alternated having pneumonia or pleurisy. For almost a year this went on. A doctor asked for a CT scan of my lungs, to make sure everything was alright, and to see the damage done by the pneumonia. By this time I was 17 and used to spending my days on the couch barely able to move, not even wanting to breathe. Then I got the phone call.

My mother called me, having just got off the phone with the hospital. She told me she was on her way home and that I needed to go into my room and pack a bag. I asked her why. "You have a blood clot in your lung," she told me. I was in shock, it felt like a bad TV episode: Teenage girl thinks nothing is really wrong, but then one day everything changed.

Within the hour my mother was with me and I was checked into the hospital. An IV was started right away, and blood was taken. I had never been good with needles, but little did I know how quickly I had to get over that.

The test results came back. They had found the reason for my PE. I had APS. My mother and I looked at each other, having never heard of this before. The doctor explained to us about APS and that it's only been in the last decade or two that most doctors even know what it is. They told me I had to be on blood thinners for the rest of my life, and that I would start out with Lovenox shots, twice a day.

I was beyond tears. I moments my life was changed completely. I had the Lovenox shots every 12 hours, for 5 months. After that, I was allowed to start my Coumadin regime. I thought this may be the end of needles, but I was wrong. I will forever have to have my levels tested at least once a month and be careful of every medication I take, and even the food I eat.

APS did not stop there in its destructive path, however it was helped along by Lupus, which I was also diagnosed with. Within a couple years of my blood clot, I became pregnant, and experienced the biggest loss of my life. I had preeclampsia, and then full eclampsia, and HELLP syndrome. I was dying in the hospital, and the baby had already died inside of me. I had to have emergency surgery, and it saved my life, but it left a gaping hole in my heart.

A few months after this, a small mix-up of my Coumadin resulted in 6 blood clots in my brain. I had mini strokes. At 20 years old I had 6 mini strokes. Luckily I recovered, and my levels were back on track. Every day I wonder if today is the day my luck runs out. I'm only 21 years old now. APS has drastically affected my life, and so has Lupus. I do whatever I can to raise awareness.

I will not let any of this beat me, but we need help. Not enough of the population realizes just what the diagnosis of APS can mean for one person and the impact that has on the rest of their life.

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es after a while. Other options have been tested, such as light-emitting visors that allow patients to move around during therapy. "But results with visors for treating SAD haven't been as promising as hoped," Postolache says.

Light therapy is usually considered a first line treatment for SAD, but it doesn't work for everyone. Studies show that certain antidepressant drugs can be effective in many cases of SAD. The antidepressant bupropion (Wellbutrin) has been approved by the U.S. Food and Drug Administration for treating SAD and for preventing winter depression. Doctors sometimes prescribe other antidepressants as well.

Growing evidence suggests that cognitive behavioral therapy (CBT)—a type of talk therapy—can also help patients who have SAD. "For the 'cognitive' part of CBT, we work with patients to identify negative self-defeating thoughts they have," says Dr. Kelly Rohan, a SAD specialist at the University of Vermont. "We try to look objectively at the thought and then reframe it into something that's more accurate, less negative, and maybe even a little more positive. The 'behavioral' part of CBT tries to teach people new behaviors to engage in when they're feeling depressed, to help them feel better."

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be good for women's heart health. About 4 to 6 months pass. I am working full time now and one afternoon developed pain in my right calf and I am unable to put weight on it. After work I go to the emergency room where they do a Venogram. I am told to stay off of my feet because I have phlebitis. At my next appointment my gynecologist stops the HRT. However, it is the early 80's and no one yet tests for APS.

In the next few months I develop frequent headaches and migraines. I am put on Imitrex injections to give myself when needed. I struggle with fatigue and migraines and continue to work. The children are attending private Catholic schools and college. The summer of 1992 I develop new symptoms. I am having visual migraines that last up to 10 minutes accompanied with blurred vision and I am unsteady. At times I feel like I'm going to fall to the right. Now I'm scared!

"Being so young, I never believed I could be having transient ischemic attacks (TIA's) or stroke symptoms."

I go to see Dr. M, our ear, nose, and throat surgeon, thinking it could be an inner ear problem. He does an MRI of the brain to rule out an acoustic neuroma. My nurse friends say not to worry unless they send you to a neurologist. One hour later the phone rings. Dr. M wants me to see Dr. B, are best neurologist. I schedule an appointment but he can't see me for 2 ½ months. Being a nurse, I tried to diagnose myself and conclude I may have multiple sclerosis (MS). I am in my 40s, a woman losing my balance and the vision in my right eye for up to 30 seconds at a time. In retrospect, I should have gone to the emergency room to speed up the process. Being so young, I never believed I could be having transient ischemic attacks (TIA's) or stroke symptoms.

I finally have my appointment with Dr. B. It is very thorough, lasting two hours. He shows me an MRI and says I do not have MS and compares the results to a patient MRI who does have MS. He tells me I have had a small (nickel size) arterial end -stroke in the left parietal lobe of my brain. He wants to test my blood for lupus anticoagulant, anticardiolipin antibodies and all the blood work a rheumatologist orders for autoimmune disorders.

About a week later Dr. B calls at 8 PM at night and states I need to stop the HRT now and start on Coumadin. I tell him my pharmacy phone number and that I will pick-up the prescription in the morning. He says no. I must have my husband pick up the prescription now and take the medication now. I am referred to a research specialist at University Hospital, Dr. Howard Smith, who gives a name to this rare disorder. "You have antiphospholipid syndrome". I have what? He gives me a pamphlet describing it. I asked several doctor friends if they know what it is. Only one surgeon says he's heard of it.

As soon as I begin Coumadin treatment all of my symptoms disappear! I go to the library and start reading everything I can on APS and the latest research. Could this be what killed Brian? Some people might have clotting in their hearts, others in their brain. Some women have miscarriages. Most patients are put on an aspirin a day, but if you have APS and it affects your heart or your brain you must take Coumadin daily and get your protime (PT/INR) drawn regularly. After years of going to the hospital for PT checks, I finally am able to check it at home with the Coaguchek system and call-in the results.

Much has happened since we unraveled the mystery of Brian's death, mom's DVT episodes, and my TIA's and stroke. My mother and my daughter, Kelly, have been diagnosed with APS. Mom takes Coumadin. My sister Valerie has had positive blood work and fibromyalgia but no symptoms. When my daughter Kelly became pregnant with my grandson, they did the blood work and placed her on an aspirin daily. Two years later, when she became pregnant with my granddaughter Chloe, she developed symptoms of a Parkinson's type tremor and was placed on heparin injections two times daily. Her symptoms disappeared. A gynecologist doctor- friend, who also had symptoms while carrying a baby girl, believes the symptoms to be related to the extra female hormones while carrying a daughter. This doctor had to be on bed rest for her pregnancy.

Two of my nieces have also been diagnosed with clotting problems. One niece has APS. She had a miscarriage and later was placed on heparin injections twice daily after conceiving with invitro fertilization. Her older sister, in her early twenties, experienced frequent stomach pain and weight loss. She needed a major surgery that found blood clots in her spleen. Doctors also did ligament repairs to improve blood flow to her stomach. Unfortunately, her ovaries did not receive adequate circulation and she was informed that she could not conceive. She has since adopted two children, a boy and girl.

My mother, daughter and myself are all part of the Duke University research study on APS. I have also been part of the Nurses' Health Study for several years. I used to belong to the Lupus Foundation, but found their articles were rarely focused on the clotting disorders of APS. We are now able to educate our children and grandchildren on APS and its symptoms. I am grateful that we now have the APS Foundation of America for information and support.

Cold Fingers and Toes? It Might Be Raynaud's

Submitted by: Tina Pohlman

When the temperature drops this winter, it's normal to feel it most in your fingers, toes, ears and nose. But if your fingers and toes regularly turn bluish or white when the temperature dips even slightly, or if they often feel numb or painful or turn red and tingle when you're stressed or cold, it may be a sign you have something called Raynaud's disease.

Raynaud's (pronounced Ray-NOSE) disease is a disorder that affects blood vessels. Estimates vary, but most studies suggest that it affects about 3-5% of the population, especially women. It can arise at any age, although it typically appears during teenage years or later.

In people with Raynaud's disease, blood vessels have an extreme response to cold temperatures and stress. The body's normal response to prolonged cold temperatures is to tighten blood vessels and reduce blood flow to the fingers, toes and other extremities. This helps to slow heat loss and keep warm blood flowing to your brain and other vital organs. Likewise, stressful situations normally trigger the release of hormones that can also cause blood vessels to narrow in your extremities.

But in people with Raynaud's, the response to cold and stress is far more rapid and severe. Just taking something out of the freezer or sitting in an air-conditioned room can trigger an attack, which may last for less than a minute or as long as a few hours. During a Raynaud's attack, the blood vessels quickly narrow and reduce the flow of blood, causing the skin to temporarily turn white, then bluish. When blood flow later returns, the skin turns red. Your fingers and toes may throb or feel numb and tingly. With severe Raynaud's, which is uncommon, prolonged or repeated episodes can cause skin sores or tissue death (gangrene).

Most cases of Raynaud's have no known cause—a condition called primary Raynaud's disease. Primary Raynaud's is typically more of a bother than a serious illness. It can often be managed with minor lifestyle changes, like wearing warm socks around the house or wearing gloves when removing things from the freezer.

When Raynaud's disease can be linked to an underlying medical condition, it's called secondary Raynaud's or Raynaud's phenomenon. Secondary Raynaud's is a more complex and typically more serious condition. It is most often caused by connective tissue disease, like scleroderma or lupus. Some of these diseases reduce blood flow to the fingers and toes. Secondary Raynaud's can also be caused by some medications that reduce blood flow, including certain blood pressure and migraine headache drugs. Treating the underlying condition or changing medications, if possible, is often the best way to reduce Raynaud's symptoms.

Physicians usually recommend non-drug treatments for patients with primary Raynaud's, because they're not at risk for tissue damage. Secondary Raynaud's may require prescription medications that help to improve blood flow and heal skin sores on fingers and toes. Be sure to talk with your doctor if you think you may have Raynaud's disease.

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Behavioral changes might include having lunch with friends, going out for a walk or volunteering in the community. "We try to identify activities that are engaging and pleasurable, and we work with patients to try to schedule them into their daily routine," says Rohan.

A preliminary study by Rohan and colleagues compared CBT to light therapy. Both were found effective at relieving SAD symptoms over 6 weeks in the winter. "We also found that people treated with CBT have less depression and less return of SAD the following winter compared to people who were treated with light therapy," Rohan says. A larger NIH-funded study is now under way to compare CBT to light therapy over 2 years of follow up.

If you're feeling blue this winter, and if the feelings last for several weeks, talk to a health care provider. "It's true that SAD goes away on its own, but that could take 5 months or more. Five months of every year is a long time to be impaired and suffering," says Rudorfer. "SAD is generally quite treatable, and the treatment options keep increasing and improving."

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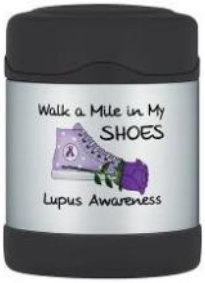

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