



# ANTIPHOSPHO...WHAT?

APS Foundation of America, Inc. Newsletter

Volume 23

Fall / Winter 2011

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!*



## The APSFA joins a Collaborative Effort with the Coordination of Rare Diseases at Sanford (CoRDS) Registry

Written by: Tina Pohlman

The CoRDS registry is a national disease registry that includes all rare diseases. Sanford Research is a non-profit research organization formed between Sanford Health and the University of South Dakota.



Research into rare diseases is often limited by many factors: lack of awareness, lack of information and the relatively small number of suitable participants for clinical trials to effectively test new treatments. Treatments for many rare diseases are symptomatic and many rare diseases in some cases may in fact share similar symptoms. Currently, patient registries are organized independently and patient information is thus kept in separate databases, making it difficult to integrate data. Establishing a central registry of persons with confirmed diagnosis of every rare disease is an innovative way to accelerate rare disease research efforts. CoRDS provides an opportunity to perform a comparative analysis across different rare diseases which may help scientists understand the disease better.

**Goal:** To work with patient advocacy organizations, healthcare providers,

researchers and patients to send information to potential participants to create a resource that links scientists conducting research studies with the patient interested in participating in the trial which will ultimately accelerate rare disease research.

### Enrollment:

- 1) Participant completes [CoRDS postcard](#) and sends to CoRDS personnel
- 2) CoRDS personnel contact participant and conducts a [brief interview](#) to gather information to send the CoRDS consent form and CoRDS questionnaire
- 3) CoRDS participants will read and sign the consent form, complete the [8 item questionnaire](#), and send the forms back to CoRDS personnel.
- 4) When CoRDS personnel receive the information, they will enter the information in the CoRDS database.
- 5) CoRDS personnel will contact the participant annually to update the participant's information and additionally if a researcher would like to contact them regarding a research study.

*\*Participants are encouraged to contact CoRDS personnel anytime during the*

*(Continued on page 7)*

## Click Below to Follow APSFA



## Patient Stories & Articles Needed!

We are in need of patient stories to feature in our newsletters. Every APS patient has a story to tell and yours could be shared with the entire APS community.

We also need related articles such as book reviews, poems, recipes, interest articles, quotes, etc.

If you are interested in sending us your story, please write to [articles@apsfa.org](mailto:articles@apsfa.org) and we will send you our guidelines.

Without your help our newsletter cannot be a success!

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## Letter from the President



Winter is fast approaching me. It has been around me, but happily it has been missing me. The squirrels are fat and furry so I think we are in for a cold winter.

We are proud to announce that we are working with another research group, CoRDS. Please see the article on page 1 for more details. We hope everyone gets involved with research project as well.

Café Press is growing again. We are adding more and more products everyday. Check out our store at <http://www.cafepress.com/apsfoundation>. 100% of the profits from these products will go to the APS Foundation of America, Inc. We should have more designs coming soon as well.

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.

Due do medical circumstances beyond our control, we will be doing our Giving Tree just a little bit different this year. We will be placing your name (and who it is in honor / memory of) underneath the appropriate ornament or present at the end of the campaign. Not to worry, you will still get your tax receipt on time. We can also send a notice of your donation (as long as a complete address is provided) to the person the donation has been made in honor/memory of, if you so choose. Thank you for supporting the APSFA.

Again, I must apologize that I am behind on some APSFA items. Between my health, my numerous doctor appointments, lab draws, and other responsibilities in my personal life I have just been swamped. I am trying to find a whole day where I can sit down and devote time to get it all done at once. Finding a whole day lately has been the problem. So, please bear with me.

That is about all the news I have to report. Once again, I hope this newsletter finds you in the best of health and with a perfect INR level. Wishing you and your family every happiness this Holiday Season and through the coming year.

Sincerely,

Tina Pohlman

President & Founder



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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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## Different Way to Donate to the APSFA This Coming Holiday Season Written by: Heidi Ponagai



The 2011 Holiday Season is right around the corner and sneaking up on us faster than you think! Now is the perfect time to start thinking about where your holiday charity donations are going this year. This page is dedicated to the many different ways you can donate to the APS Foundation of America, Inc. during this holiday season as well as the rest of the year.

### Donation Ideas

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

\* We accept donation 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, money orders and credit card donations through PayPal.

\* On our [website](#) we have APS informational booklets, various awareness pins, postcards and APSFA pens for sale. All profits of these sales go to the foundation.

\* We also have [continuous monthly donation "subscriptions"](#) available in the amounts of \$10, \$15, \$20 and \$25 per month for one year. These can be done by PayPal or by check if you wish.

\* On our [shopping page](#), we have links to [Amazon](#) as well as [GoodSearch shopping](#). When you use these sites to do your online shopping, the APSFA gets a small percentage of the sales!

All donations made to the APSFA are tax deductible and we send out receipts for all donations we receive for tax purposes. Please see our website for more information on making donations to the APSFA at <http://www.apsfa.org/donate.htm>.

Please be sure to have all donations for 2011 posted dated by 12/31/2011.

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

### APSFA 6th Annual Giving Tree

The APSFA "Giving Tree" is a holiday tradition. Our tree will be planted by the time this newsletter goes out to print, so please see our [website](#) for more details and how to decorate our tree!

There will be buttons for making special "Giving Tree" ornament donations on the site. Ornaments will come in different shapes & colors to represent different donations denominations.

The "Giving Tree" will work similar to past years but due do medical circumstances beyond our control, we will be doing our Giving Tree just a little bit different this year. We will be placing your name (and who it is in honor / memory of) underneath the appropriate ornament or present at the

campaign. Not to worry, you will still get your tax receipt on time. We can also send a notice of your donation (as long as a complete address is provided) to the person the donation has been made in honor/memory of, if you so choose.

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

Information about our tree can be found here: <http://www.apsfa.org/givingtree.htm>



### The APSFA Café Press Online Store

We have a wide selection of APSFA, APS, Lupus, Hughes, infant loss & thrombosis gear located in our [Café Press store](#).

With every item purchased, the APSFA receives a small donation. We have made over \$1300 so far in 2011 just with Café Press sales!! Thank you to everyone who's purchased our items.

For those people who are not familiar with our store, we have items like t-shirts, sweat-shirts, buttons, magnets, pictures, teddy bears, tote bags, jewelry and stickers to name a few. We also sell a lot of our APSF log books which are a great tool for any APS

patient. They are great to bring to appointments because all of the information you need is right there.



This year is the 6th year for our annual exclusive APSFA keepsake ornament. We picked a snowflake to adorn our ornaments because all snowflakes are different, just like all every APS patient is different. The ornaments are \$8.99 each and are made of porcelain.

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



## If Someone Taking Coumadin® Hits His / Her Head

Written by: Al Lodwick, RPh, MA

I have done an extensive search of the medical literature for this topic, since I served as an expert witness in a murder trial where the central issue was a head injury suffered by the deceased.

Any head injury, no matter how slight it may seem at the time, is cause for concern when a person is taking warfarin. This does not mean that an ambulance ride to the hospital is always necessary. In fact, it may take up to a week for there to be any indication of a brain injury. It is possible to have tests done too soon after the injury which can lead to a false sense of security. Close observation for a long period of time may be necessary. Do not overlook the fact that a brain injury may cause the injured person to develop poor judgment causing them to not relate their condition to significant others.

I believe that the above statement can be backed-up by reports in the medical literature. Hylek and Singer studied the records of 121 people hospitalized for bleeding in the head. 77 of these had bleeding in the brain which was fatal 46% of the time 44 had bleeding in the area between the skull and the brain (subdural bleeding). This was fatal 20% of the time. The symptoms that caused the person to be admitted to the hospital included headache, nausea and vomiting, unresponsiveness, paralysis on one side of the body, inability to communicate and confusion. The people who had bleeding into the brain were usually hospitalized sooner (78% within 24 hours) after symptoms developed than were those who had subdural bleeding (27% took 3 to 7 days and 21% were not hospitalized until more than a week after symptoms devel-

oped). Besides the 46% who died from bleeds into the brain, another 45% left the hospital with some type of neurological problem. Only 9% of these patients were normal at the time of discharge. For those with subdural bleeding, 59% left the hospital with some type of neurological problem while 20% were normal at that time.

Mina et al. studied the records of 380 patients who were taking anti-coagulants (aspirin and many other medications in addition to warfarin) who were admitted with

trauma. They had a dramatic finding that 60% of people who were anticoagulated when they fell down stairs died. They concluded that people who were anticoagulated, even with aspirin alone, were four to five times more likely to die from a head injury than were people not taking anticoagulants.

There have been some controversies as to how much risk people are at if they suffer a head injury and are taking warfarin. A study by Li et al. found these people are at moderate or higher risk of suffering an intracranial (inside the head) injury. They recommend that there should be a CT scan done on all patients who are taking warfarin and suffer head trauma. One of my patients was shopping for clothes at Wal-Mart. An article of clothing fell off its hanger. She bent

down to pick it up and hit her face on the rack sticking out from the wall. She went to the Emergency Room the next day after it happened because her entire face was bruised. No internal bleeding was found. After one week she noticed that she was having trouble seeing and went back to the ER. This time a

small bleed into the subdural area was noted. She had evidently been bleeding very slightly over the course of one week. Her INR at the time was 2.7, so she was not overdosed on warfarin. How do you decide if an injury is serious enough to require emergency evaluation? Several studies have categorized patients as high, moderate and low

risk. Anyone who has an altered state of consciousness, an obvious skull wound, who does not remember what caused the head injury, seizures, vomiting, or if the cause of the injury is unknown should seek emergency treatment. If the emergency treatment findings are negative, do not be lulled into a false sense of security. Many of these people were not admitted to the hospital for more than a week after the injury. I recently saw this happen to one of my long-term patients. She fell and hit her head quite hard. Her daughter called me and asked my advice. The family decided that since she seemed to have not been harmed they would simply watch her at home. After several days she began talking nonsense. The family took her to the

*(Continued on page 9)*





## Holiday Stress? Let's Enjoy

Written by: Robert Phillips, Ph.D.,

a charter member of the AARDA's Scientific Advisory Board & practicing psychologist on Long Island, NY. He is the founder and director of the Center for Coping.

Believe it or not, there are as many people stressed out by the holidays as there are who enjoy them! Which category do you fall in?

For many people with autoimmune diseases, the level of stress already being experienced is higher than desirable. The stress of the holidays can push them over the top. Holiday time can be upsetting and stressful for a variety of reasons, not just the typical ones—such as buying or wrapping gifts, writing cards, planning, cooking and coordinating.

So you fall into the “holiday stress” category. What can you do? You can implement strategies that will help you deal better with this time of year. In fact, you might benefit by planning for and dealing with the holiday season the same way that you would deal with any unpleasant situation. The goal, of course, is to try to turn what you're anticipating as an unpleasant situation into a more pleasant, enjoyable time. Yes, it's possible.

**Pinpoint your stress.** The first step is to determine exactly what is stressful for you. It is specifically relate to the holidays (buying gifts, attending dreaded family get-togethers, etc)? Or it is more the stress of living with autoimmune disease just seems to be exacerbated by the joy that others seem to be experiencing during holiday times? Start by making a list of the things that are stressful for you.

**Divide and conquer.** Once you have pinpointed the specific things that are bothering you, divide the items into two categories—things you can do something about and things you can't.

In the first category, things that can change, start jotting down specific steps to take to make certain changes. Make your steps as small as possible since being able to check them off as you accomplished them can be a terrific motivator to continue efforts. If you're not sure what steps to take, consider discussing this with the successful “action-orientated” people in your life.

In the second category, things that cannot change, you'll want to work on your thinking. Recognize that there are probably plenty of people out there who are dealing with the same or similar unchangeable stressors, but they are dealing with them better than you are. That doesn't mean that you should be comparing yourself to them. It does mean that if they can handle it better, so can you! This is the first step in changing your thinking, keeping your mind open to improving your outlook.

Your attitude can make a big difference. Ask yourself why you are allowing yourself to be as upset as you are about a particular situation. Ask yourself how long you're going to allow yourself to feel

this way. Ask yourself what other, more positive, constructive ways you can look at your given situation.

**Utilize additional stress relievers.** What else can you do to improve your overall state of mind? Here are some common-sense pointers to include in **any** stress-reducing plan.

- \* Eat properly (although this may be difficult with all the holiday foods.)
- \* Get enough appropriate exercise.
- \* Cut back on harmful habits (such as smoking or drinking).
- \* Develop and maintain a more positive mental attitude.
- \* Use relaxation techniques regularly.
- \* Get plenty of rest ... but don't rest to escape.
- \* Minimize worrying, especially about things that are out of your control.
- \* Enjoy the presence of your support network, family members and friends who care about you.
- \* Schedule time for things you enjoy. This is not a luxury; it's a necessary.



With any stress-relieving strategy that you plan to use, jot down small, easily-achievable goals and do what you can to accomplish them.

Finally, if you are still having trouble dealing with stress on your own, consider seeking the help of a mental health professional. Being able to talk to someone and having someone help you with successful techniques, can make a big difference.

Holiday time need not be unpleasant. Given the stress in our world and the stress of living with autoimmune disease, it makes sense to do what you can do to enjoy this time of year as much as possible. Please try to have a happy—and healthy—holiday!

Dr. Phillips is the author of numerous articles and more than 30 books on a variety of subjects in psychology (including Coping with Lupus, Successful Living with Scleroderma and Coping with Endometriosis). For information on the Center of Coping, see [www.coping.com](http://www.coping.com).



## Someone Call Dr. House

Written by: Kelesy Richardson



My name is Kelsey. I am now 21 years old. When I turned 18, I started birth control pills, but within in two weeks, I felt like there was something in my right eye. My vision was blurred and when I covered my eye, I had a blind spot.

I went to see my eye doctor thinking that I had an eyelash caught or something. He dilated my eyes and started the exam. He suddenly stopped and said, "I need to make a call. I can't help you." Without another word, he left the room. He left me sitting there. I was so confused. He came

back and gave me a card and told me that I had a retina abnormality and that I need to see the Retina Specialist tonight and that he had set me up with an appointment.

I called my mom and she left work early to come with me. At the Specialist office we just sat in silence in the waiting room for what seemed like an eternity. Finally, we went back into the room and the nurse started doing a test. She told me to look at her eyes, cover my left eye and use my peripheral vision to tell her how many fingers she is holding up. Everything was going normal until she held her hand by her hip. I couldn't see her hand! It was like it had disappeared.

She went to tell the doctor and they did an angiogram on my eye and there was a blood clot in my eye! The next day I went to my medical doctor. She told me to stop the birth control and she ran some tests. For two months, I went back and forth with doctor's running tests. I remember one doctor looking at his coworker and saying, "We need to call Doctor House!

How does a healthy 18 year old get a blood clot!?" Finally, I switched doctors and within one week, my new doctor knew what was going on. In February of 2009, I was diagnosed with Antiphospholipid Antibody Syndrome. She started me on Warfarin for six months. I now take one aspirin once daily.

I still have partial blindness in my right eye. My Retina Specialist told me I would have it for the rest of my life because my eye had been damaged too much during the 2 months before my diagnoses. I am so thankful every day that my doctor figured out what was wrong before I got a new blood clot!

## For Children Lost to APS

Written by: Shelley Walker

A poem for my daughter Melissa, lost at 28 weeks.

I have lost many but I held her as she past so apart from the two I was fortunate to raise I will forever embrace her in my heart.

Oh, life of my life, my sweet precious child.

Who grew near my heart so tender so mild.

My heart holds forever my sweet little dove.

Your beautiful soul which I nurtured and love.

As each new day passes I look to the skies.

I forever remember the sound of your cries.

Our hearts once beat together long before you were born.

Soon again they will beat when my heart has worn.

So rest now my darling and wait there for me.

Till my soul is called into eternity.

*I have an  
Angel   
waiting in heaven!*



# Gifts that Matter: Ten Helpful Gift Ideas

Submitted by: Heidi Ponagai



At this time of year, friends, family and neighbors get the holiday spirit and want to help out and give thoughtful gifts. What do you tell them? Start by explaining how small gestures can be priceless. And then be prepared to offer specific ideas for gifts that will make life easier and more enjoyable for you or the APS patient in your life.

Can't think of anything off hand? These ten ideas just may fit needs you didn't even know you had.

1. **A meal and a conversation.** Getting out and about can be challenging and tiring for both you or the APS patient in your life. But not getting out can lead to a sense of isolation. So when asked what people can give you this holiday, tell them you'd really enjoy their company and perhaps a home cooked meal. Fresh meals prepared and cooked in your home are even better. The aroma is free and the sensory experience is great for restoring the appetite in both you or the APS patient in your life. When people prepare fresh meals in your home instead of their own, you or your loved one get the benefit of talking, laughing and maybe even helping during the cooking process.
2. **A set schedule for a weekly call.** Knowing that someone will be phoning at a set times allows you to plan your schedule around calls and gives everyone something to look forward to.
3. **Help with the chores.** Grocery shopping, trips to the library, picking up prescriptions, climbing up on ladders to change a light bulb, cleaning the fridge—these tasks take

up valuable energy and time or don't get done. A donation of chore time can be invaluable.

4. **A stockpile of the basics.** Ask people to provide a year's supply of paper products, cleaning supplies, and other bulk items.
5. **Home organization.** Having a highly organized neighbor or visiting niece reorganize closets and shelves in your home to make things easier for the you or the APS patient to reach and use—making both of your lives better.
6. **A well-organized coupon collection.** Who has time to cut coupons? Having someone else collect coupons and stick them in an organizer can drastically reduce household expenses.
7. **A festive home—without all the work.** Invite friends and family to come over and decorate the house for the holidays. Familiar sights and scents of holiday cheer, for the soft lights of the burning candles to the scent of fresh pine, can do wonders to lift mood and restore a sense of normalcy to your holiday experience.
8. **Grocery delivery.** Out of town family members can call the local grocery store and arrange for favorite foods to be delivered directly to the home.
9. **One-month trial subscription to Netflix.** This is easy entertainment for anyone! What's better than your favorite holiday movies showing up in the mailbox for you to watch at your convenience.
10. **Hand-written gratitude letters.** Encourage loved ones to write a brief note to the APS patient saying what they admire most about him or her, or how grateful they are for something they have done for them or even sharing a favorite memory. This gives the APS patient a necessary boost in mood and all you have to do is share the joy.

Adapted from StrokeSmart Nov/Dec 2008

*enrollment process if they have any questions*

## Want to become a CoRDS Partner or Enroll in the Registry?

Click on the Organization or Participant Tabs to find all the information you need to become a CoRDS partner and to enroll in the Registry.

## Have Questions? Please Contact:

Liz Donohue: 605.312.6413  
Lauren Beaumont: 605.312.6423

## Mailing Address

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Web: <http://sanfordresearch.org/CoRDS>



## Seronegative APS & Lupus...What a Combination!

Written by: Tina Pohlman

I have had a long battle with [Sero-negative APS \(SNAPS\)](#). I was finally diagnosed in 2002. It is formally documented in my records as Thrombophilia with clinical features of [APS](#). I also have Thrombophilia secondary to [Lipoprotein\(a\)](#), [Livedo](#), [Raynaud's](#) and [Lupus](#).

My problems started out in grade school when I developed [Fifth Disease](#). After that I started having problems with headaches and bloody noses. In high school, I got the [Epstein Barr Virus \(EBV\)](#)



and never have been the same since. I had dizzy (vertigo) spells most of my high school and my first parts of college. My blood pressure would spike during those times. I would have problems seeing, speaking and walking, my body would twitch and I would have these horrible headaches. I was told that it was anxiety and that I didn't want to be in school. I was an A/B student. From 1985 to 1992, I really wasn't feeling well at all. I got a reprieve and finished my degree in Public Health Education and started getting active with the US Coast Guard & Auxiliary in hopes of being accepted into Officer Candidate School. But in 2000, I started having more neurological problems and unfortunately, was forced to stop pursuing the dream of being an Officer in the US Coast Guard.

It started again one summer night in 2002, I had a [TIA \(transient ischemic attack\)](#) with an [amaurosis fugax](#) (temporarily loss of vision in the eye). The ER felt it was a

"complicated migraine", as I was "too young to have these kinds of problems".

They started me on aspirin and I stopped the birth control I was taking as I sensed there was a bigger problem at play. Two

months later I ended up in the hospital with a [DVT \(Deep Vein Thrombosis\)](#). I was started on Coumadin® and after much trial and error my therapeutic range was set at 2.5-3.5 because I managed to re-clot on Coumadin®. In 2006, I was placed on Plaquenil® as that was becoming a standard treatment for APS and with the Lupus symptoms; it was a win-win situation. I still have TIAs & feel like I am clotting despite having a therapeutic INR and being on aspirin and Plaquenil®.

I have also had a [heart attack](#). The ER thought it was "acid reflux" and sent me home. After not feeling well for two months, I finally pushed for an answer and they did a [perfusion study](#) of my heart. They found a previous posterior MI (aka Heart attack). One and a half years later,

the angiogram shows my arteries clear so of course it was "acid reflux" in their eyes and that perfusion study must have just been wrong. It was ultimately decided that I may have Cardiac Syndrome X. Other than the [supraventricular tachycardia](#), the occasional run of [PVCs](#) & [PACs](#) and [mitral valve prolapse](#) that has gotten more pronounced over the years; it is ok. My kidneys give me problems with decreased kidney functions and protein in my urine but is always blamed on something else or dismissed. I guess it isn't bad enough in their eyes, yet.

Getting doctors to listen to me and take me serious has been a battle, especially in the ER. I never got a full clotting panel until I started pushing for answers. That is when I got one positive test that was "equivocal". Because of this, I started a medical symptoms journal to help track my symptoms, INR and any other patterns I noticed.

I also started a photo journal for the times that my face is drooping but I know by time I get to the ER or call 911 and actually get seen it will be better. I have shown these pictures to my neurologist who said that yes that is a TIA that is triggering the migraines, specifically [vertebrobasilar TIAs](#). The pictures I had been taking helped save me and get the diagnosis. The neurologist also felt what I was having in high school and college were TIAs, not the panic attacks or complicated migraines they thought I was having. I also take pictures of the various rashes that I get. Those

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pictures have also helped me get on Plaquenil®. They have helped me get better treatment options from my dermatologist. I have the left sided weakness & balance issues, documented by an independent physical therapist, which are consistent with her 80+ year stroke patients. That specific therapy session was actually a good day for me physically, if that says anything. Sadly, the vertebral TIA's are building up have caused hearing loss and they suspect is causing the increased loss of balance.

As time has gone on, my Raynauds/Livedo has gotten worse. My headaches & vertigo come in go in streaks. The neurologist, ENT and GP have decided the vertigo was a microvascular issue many years ago. My guess is that it is connected to the Raynauds/livedo which is also microvascular. I have problems with cystitis that seems to only come with a flare. The urologist feels this is due to microvascular changes in my

bladder from my autoimmune & clotting problems.

end, I am told there is nothing more they can do for me.

“This is my “new normal”. I have learning still to keep fighting and pushing for answers and to keep listening my intuition; my gut feelings are generally right on. But in the end, I am told there is nothing more they can do for me.”

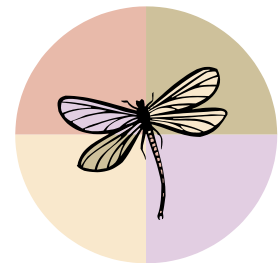
There are times I think I can get back to normal. But every time, I start getting back to my old "normal" or picking up my pace my INR drops or something else happens. I just wish I could predict how I will feel later on that

Looking back, I was never really healthy. I always had some sort of cold, some sort of ear infection, always taking antibiotics or Dimetapp. I was always tired and just never could keep up with my classmates. I was always cold and would turn all these funny shades of red, white and purplish/blue. At the time, we just thought I got frostbite easy. I never really did ok in the sun. I got “sun sick” very easy. Now I wonder how long I really was sick.

week or the next day, etc. Pain, vertigo & fatigue are my biggest problems and these recurring TIA's. APS & Lupus makes it very hard to hold down a paying job and live a normal life.

I can no longer do contract work or teach EMS classes because of memory & health issues. I just go with it day by day do lots of volunteering.

This is my “new normal”. I have learning still to keep fighting and pushing for answers and to keep listening my intuition; my gut feelings are generally right on. But in the



(Continued from page 4)

emergency room. Because of her advanced age and the large amount of blood in her head, it was decided that she was unlikely to survive surgery. Her doctors and family both feared that the end was near. However, she recovered and was able to return home at nearly her usual state of health. However, the warfarin was not re-started.

I have been an expert witness in a murder trial where the guilt or innocence of the accused turned on whether or not the deceased merely

fell and hit his head, or was he pushed down a flight of stairs or was he hit over the head. Whether or not a person taking warfarin is safe after hitting his/her head is probably the most difficult decision there is to make concerning this drug.

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**Editor's Note:** As some of you may know, Tina, our President, took a serious fall down a flight of stairs. No CT was done initially, despite her INR being 3.7. She finally got a CT a week later when her headaches, nausea and “feeling out of it” increased. Luckily the CT was negative and she is healing

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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.

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