ANTIPHOSPHO...WHAT?

APS Foundation of America, Inc. Newsletter

Volume 22 Summer/Fall 2011

The APSFA Helps Sponsor UTMB Study

Written by: Tina Polhman

This is exciting news that I am sure many of you have been waiting to hear. The APS Foundation of America, Inc is helping sponsor ***An Immunoassay for detection of antibodies to domain I of b2 glycoprotein I*** at University of Texas Medical Branch (UTMB).

Under the supervision of one of our medical advisers, Silvia Pierangeli, PhD, Holly Bentz, a bright 4th year medical student at UTMB who initially rotated through UTMB in the clinic and has shown interest in APS research, will be working on a more specific b2 glycoprotein I test kit.

According to Holly, "A newer diagnostic modality is via the detection of b_2GPI antibodies. b_2GPI has been shown to be the antigenic target of aPL. While this test has been shown to be more specific than aCL, there is a subset of patients who are positive for anti-b_2GPI antibodies that never go on to manifest APS. Further studies has elucidated the structure of b2GPI revealing 5 protein domains. Sufficient evidence has accumulated showing that domain 1 is the primary epitope for aPL antibodies and that these anti-domain I antibodies were associated with a higher incidence of pathological events in APS as compared to antibodies to other domains. Therefore, recombinant isolates of domain 1 of b_2GPI we hope to develop an ELISA test that will detect only antibodies towards domain I of b_2GPI, thus identifying pathologic forms of the antibody responsible for APS. We have serum samples from true positives, as well as true negatives. If we are successful, this could allow clinicians to more precisely decide which patients require anticoagulation, and which patients could be safely spared the morbidity of long-term anticoagulation."

We are also please to announce that the APSFA will be mentioned as a sponsor in any publications and journal articles related to this project.

We will keep you posted on updates as we receive them from Holly and Dr. Pierangeli.

We at the APSFA must thank UTMB for giving us this opportunity to work with them. We also thank our wonderful donors who have made this sponsorship possible. We will be writing for larger grants so we can sponsor larger projects or larger portions of a projects in the future. We would still like to raise another $2000.00 for this project to add on to our current sponsorship. If you or your company would like to donate to this project, please feel free to donate to us at: http://www.apsfa.org/donate.htm Please write "Research Fund" in the memo so it is earmarked properly to ensure that your donation goes into the proper account.

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 and we will send you our guidelines.

Without your help our newsletter cannot be a success!

Inside this issue:

Letter from the President

Fall is upon us already. The squirrels are busy burying their nuts and the leaves in Wisconsin are changing colors. Summer left as fast as she came in.

I am pleased to announce that the APSFA has helped sponsor our first study with University of Texas Medical Branch. Please read more about this sponsorship on the cover of this newsletter.

We are also please 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 can not 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.

You will also notice an upgrade to our links page at http://www.apsfa.org/links.htm The service provider we were using stopped providing their services so, we switched to a new service. While it is costing us more per year it will be less work for both Heidi, Cindi & I. We feel it is easier to navigate and search as well and have received many compliments on it already.

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.

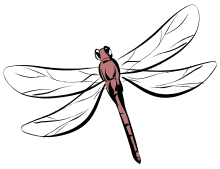
Please remember to sign up for the e-Newsletter at http://tinyurl.com/3rvb379 . We are planning on sending special articles out that will only be available to those that are on our email list.

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.

Sincerely,

Tina Pohlman
President & Founder



APSFA Board of Directors

PRESIDENT, CO-FOUNDER, EXECUTIVE DIRECTOR
Tina Pohlman, WI

VICE PRESIDENT, CO-FOUNDER, WEBMASTER
Heidi Ponagai, MI

SECRETARY
Cindi Brookes, CA

CO-FOUNDER
Todd Ponagai, MI

MEDICAL ADVISORS

Thomas L. Ortel, MD, PhD
Director Duke Clinical Coagulation and Platelet Immunology Laboratories
Director Anticoagulation Management Service

Robert Roubey, MD
Division of Rheumatology & Immunology
University of North Carolina at Chapel Hill

Gale A. McCarty MD, FACP, FACR
President, RheumEd Consulting
Harborside, Maine

Keith R. McCrae, MD
Division of Rheumatology & Immunology
University of North Carolina at Chapel Hill

Al Lodwick, RPh, MA
Certified Anticoagulation Care Provider
Founder of the Warfarin Institute of America

Sheldon Paul Blau, MD
School of Medicine of the State University of New York at Stony Brook
Fellow of the American College of Physicians and a founding Fellow of the American College of Rheumatology

Adedayo A. Onitilo, MD, MSCR
Oncologist/Hematologist
Master of Clinical Science Research, Medical University of South Carolina
Assistant Director of Clinical Research-Eastern Division, Marshfield Clinic, Weston, WI

Audra Ford, MD
Family Medicine, Augusta, Georgia

APS & CAPS Galore

Written by: Stephane Bedard

My name is Stephane Bedard from Laval, Quebec, Canada. While I was at work, I was experiencing what I thought was muscular pain reminiscent of a hernia. At the beginning I did not get too worried and kept on working for a week. By the week's end I was trying to sleep and the pain had gotten so bad that I decided to go to a nearby hospital's emergency. There I got much worst. The doctors thought that I either had pneumonia or a pulmonary embolism. At the time I was only 36 years old. The emergency doctor had consulted a pulmonologists who thought I was too young for a pulmonary embolism. I could hear them argue over the phone and they opted to give me antibiotics as well as heparin just in case. The pain was excruciating. The next day I was taken by ambulance to another hospital for a detailed scan. It turned out to be performed by the same pulmonologists who had argued with the emergency doctor the day before. To his astonishment, here it was clear as day, a pulmonary embolism. Had the emergency doctor not given me heparin the night before, I would surely have died. So I was hospitalized for three weeks and slowly the clot shrunk and I was given Coumadin for six months.

At the end of the six months, I had to stop taking Coumadin so that I could be tested for the antiphospholipid antibody. It came back positive. Three weeks had gone by without taking any Coumadin. The day after my hematologist informed me that I had to return to a daily dose of Coumadin I had a second pulmonary embolism. Since I already knew what it felt like, I didn't wait long before rushing to the emergency. That brought me another two weeks hospitalization.

A couple of years later on my wife's birthday, I got a third pulmonary embolism while my INR was therapeutic at 2.7. The hematologist decided to install a filter in my vena cava to prevent clots formed in the legs from gravitating towards my lungs. That seems to have done the trick for I have not had another pulmonary embolism since.

In the next ten years I had a number of relatively mild complications. I started having kidney issues, ischemia in the foot and immune related issues. On the 12th of January 2009, I went to the emergency suffering from abdominal pain. For two weeks the doctors were unable to give me a clear cut diagnosis saying that I probably had lymphatic cancer. My lymphatic nodes were swollen throughout my body. I was then transferred by ambulance to a research and teaching hospital and I was handed over to the internal medicine department. After a week, I was told that I was suffering from catastrophic antiphospholipid syndrome and I was rushed to the ICU and given plasma exchange. Maybe an hour after the procedure I felt a whole lot better.

Unfortunately the story did not end there. I had no less than 13 relapses during that same year. Complications piled-up and I remained hospitalized for a total of 7 months, I visited the ICU four times, I returned to the emergency at least 4 times and I had so many plasma exchange sessions that I can't count them. Before I got the plasma exchange, my lungs, kidneys, liver, heart, spleen and adrenal gland all took a beating. It was too late for my kidneys but all other organs eventually recovered.

Today, I have to go to dialysis three times a week; I take a ludicrous amount of pills, injections and other products but I am alive and able to resume many of my normal activities. Unfortunately, it looks like I will not be able to return to work this time around. My new full time job will be to manage my disease and learn all I can about CAPS. I guess I am lucky. I have a fantastic spouse who supported me throughout this ordeal and I have a superb team of doctors and staff who looked after me as if I was family.

Pradaxa®: Is the Convenience Worth It?

Written by: Tina Pohlman

PRADAXA® is a prescription blood-thinning medicine used to reduce the risk of stroke and blood clots in people with atrial fibrillation not caused by a heart valve problem. With atrial fibrillation, part of the heart does not beat the way it should. This can cause blood clots to form, increasing your risk of a stroke. PRADAXA lowers the chance of blood clots forming in your body.[1]

This drug is not approved for any other issues; including Antiphospholipid Antibody Syndrome.[2]

After interviewing Craig Cole, MD, Hematologist at Gundersen Lutheran Medical Center. I am surprised it was it was approved by the FDA. While the marketing & prescribing information do not say much, the grey information is starting to come out and was discussed at the recent American Society of Hematologists (ASH) meeting, which the APSFA was invited to attend.

After having many problems keeping my INR regulated, I thought Pradaxa® was going to be my answer. I am tired of weekly plus INR draws – the whole nine yards. Initially, my big concern was there is no way to reverse it.[2] There is still no way to reverse it. "While the prescribing information states there are things the doctors can try, they do not work. This is being found out in after market research and was discussed at the recent ASH meeting," according to Dr. Cole.

During our discussion there were many more new things that I have learned about the "grey area" that is being reported in after market effects and were discussed at the ASH meeting. According to Dr. Cole:

- This drug has an extremely short half life, meaning if you are two hours late taking it, you are risking a clotting event.
- Pradaxa® causes stomach issues[2] but you can not take anything for the stomach issues (no Tums, no Proton Pump Inhibitors, nothing) as it will not let the Pradaxa® absorb, and you will risk a clotting event.
- If you have problems with your metabolism being too fast or too slow, this can cause problems. Too fast, you risk a clot, to slow you risk a bleed.
- Pradaxa® actually has a higher risk of drug failure than warfarin does. Yes, I said higher.
- Again, I will stress there is no way to reverse Pradaxa®.[2]
- If you have kidney issues or kidney failure and start bleeding through them, as that is the way Pradaxa® is excreted, you are probably looking at death. No, dialysis will not work as Pradaxa® is too small and passes through the dialysis filters. The Pradaxa® just will never leave your system. This is why Boehringer Ingelheim has these disclaimers on their website regarding kidney issues.[1]
- The company, Boehringer Ingelheim, claims they are trying to make a drug to reverse it but ASH and Dr. Cole have yet to any papers or studies regarding this.
- There is no way to monitor Pradaxa®. I am sure you are saying, but it is weight based, no not really. It is set up as a one dose fits all and a separate dose for those who have kidney issues.[2] They do not have any way to see what your blood levels are at all. As an example, Lovenox® can be monitored by an Anti-Xa or aPTT.[3] If you start clotting on Pradaxa®, they have no way to know if you are getting enough Pradaxa® and it doesn't effect any current tests that are used. Your blood will look "normal".

According to Dr. Cole, the reason this drug is only used for atrial fib-

(Continued on page 9)

The Way *Eye* See It...An Update on Antimalarial Eye Toxicity Monitoring

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

Antimalarial Therapies and Eye Toxicity. Hydroxychloroquine (HCQ) has been used for over 50 yrs in many autoimmune diseases (eg. lupus, rheumatoid arthritis) to decrease symptoms, disease activity, and damage. It is one of several drugs called anti-malarials because the first one, Chloroquine (CQ), was used for malaria. HCQ differs from CQ by "hydroxyl" change, hence its name. As lupus shares some symptoms and causes with antiphospholipid antibody syndrome (APS), drugs used in lupus are used in APS. Proper antimalarial use involves patient counseling about expected side effects, right dosing for weight, and periodic eye toxicity monitoring. This article addresses only eye toxicity.

Rarely, eye problems involve a) the retina, the "camera film" part of the eye; b) the macula, a yellow spot in the retina where central visual sharpness and color are; The connection between CQ and retinal changes have been known since the 1950s: the change was a late finding called "bull's eye maculopathy or retinopathy" (reviewed in 1). The word "-opathy" means pathology , eg. "something's wrong." Only *a few cases* of HCQ toxicity were found because the "hydroxyl" change was protective. Risk relates to dosage over time, which is why physician comanagement and patient compliance are important.

Rheumatologists, ophthalmologists, and optometrists provide careful follow-up to prevent eye toxicity-but times and technology change (that's progress!), so there are some *new recommendations* for monitoring (Table 1). Patients should keep a healthy weight, use sunglasses, work with their primary care providers in controlling all medical conditions that affect vision and blood vessel supply (eg. diabetes, hypertension, and high blood lipids), and get their periodic eye exams by a specialist to find changes *when they are early and reversible*. *Most patients do not perceive vision sharpness (acuity) or color vision changes-they are found ONLY BY TESTING.*

Only 1.7% (21/1207) patients on HCQ showed possible eye toxicity: only 1 of the 21 had true eye toxicity. (2). Gender or race don't relate to risk; older patients may have more problems with these drugs, due to changes in blood vessels with age and/or coexisting eye conditions, or slower drug metabolism. [In over 25 years of practice at academic rheumatology units/practices in the US and abroad, with very frequent HCQ prescription usage, I have found only 6 cases of *definite* HCQ toxicity identified by eye exams-*the patients were asymptomatic*. With stopping HCQ, 4 improved over several months: 2 who had other medical conditions giving retinal changes (eg. *probable or possible* HCQ toxicity) did not improve, but no one had progressive vision loss].

The incidence of eye toxicity was <1% of 3200 patients for HCQ over the first 5-7 yrs , rising to several % over 15-20 yrs of use (3). For CQ, safe dosage = 3.5 mg/kg of weight a day, and for HCQ, safe dosage = 6.5 mg/kg of weight a day.

Old (and New) Eye Tests. An Amsler grid test finds areas of vision loss patients did not perceive. A more advanced test is the Amsler red grid. New recommendations are that the Amsler grid be replaced by *Humphrey 10-2 (white) automated visual field testing*. Since early toxicity occurs at 2 areas in the macula, Humphrey 10-2 is better because more area is tested. *Multifocal electroretinography (mfERG)* which records electricity from all over the retina is a more objective visual field test (4).

Spectral domain ocular concerted tomography (SD-OCT) gives a detailed look at the special retinal areas and It can pick up anti-malarial toxicity earlier when there are no other retinal changes.

Color vision tests are now not considered reliable enough to detect early eye toxicity.

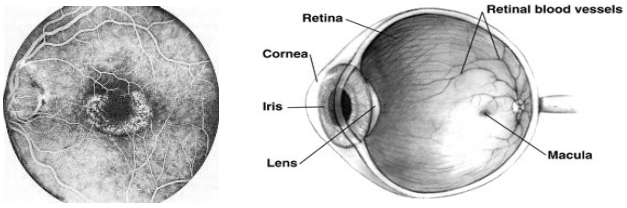


Fig. 1 "Bull's Eye" Maculopathy . L: the retina at the back of the eye, with the target-like "Bull's Eye Maculopathy" at center. At 9 o'clock the optic nerve and blood vessels enter the eyeball, and branch out. R: a cross section of the eye (1).

(Continued on page 6)

(Continued from page 5)

Table 1. New Recommendations for Anti-Malarial Eye Toxicity Monitoring

Baseline Eye Exam As a Reference Point and Screening for Maculopathy

Screening after 5 Years on Drug (Sooner If Risk Factors Are Present)

Humphrey 10-2 Visual Fields With Repeat Testing If New Areas of Vision Loss Appear

Ophthalmoscopy Not Reliable-"Bull's Eye Maculopathy" A LATE Retinal Change

Screening with One of These Newer Objective Tests to Help Earlier Detection:

SD-OCT: More Sensitive Than Visual Fields, Visualizes Early Foveal Damage

Mf-ERG: An Objective Visual Field Test

Dosing for HCQ:

400 mg a day for women >5 ft 7 in.; men >5 ft 5 in. (lean body weight important)

Renal or Hepatic Disease-lowered drug clearance (4)

Treatment of Anti-Malarial Toxicity. Benefits are weighed vs. the risks: if HCQ is stopped, disease flares, as protective effects are lost. *Stopping the medication is the usual approach*. Anti-malarials stay in tissues over time-it takes weeks to months to be cleared. Cessation of the drug does not always result in sustained improved vision.

Bottom Line. Patients on anti-malarials should discuss these new recommendations with their rheumatologists and eye doctors, so that *everyone is on the same page*. Patients should be their own best advocates by discussing eye testing with their providers, as guidelines often evolve into accepted "standards of care" over time.

References

Roque MR et al: CQ and HCQ Toxicity. **Medscape Review** Jan 2011 (www.medscape.com).

Levy GD et al: Incidence of HCQ retinopathy in 1,207 patients in a large multicenter outpatient practice. **Arthritis Rheum** Aug 1997;40(8):1482-87

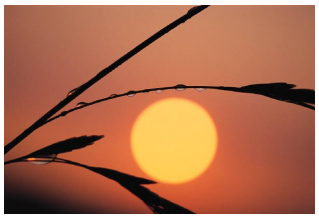
Wolfe F, Marmor MF: Rates and predictors of HCQ retinal toxicity in patients with RA and SLE. **Arthritis Care Res** 2010;62:775-784.

Marmor MF et al: Revised recommendations for CQ and HCQ Retinopathy. **Ophthalmology** Feb 2011;118(2):415-422.

A Letter to APS

Written by: Rebecca Jarquin

You squeeze the air from my lungs,
yet I keep on breathing.
You inject pain into my joints,
yet I keep on walking.
You cloud my memory with fog,
yet I keep on thinking.
You numb my limbs with pins and needles,
yet I keep on moving.
You sap my last bit of energy,
yet I keep on rising.
To the people around me
I sound the same,
I look the same.
But I know what they say about you is true;
you are an invisible intruder.
Yet I keep on fighting.



The Power of Journal Therapy

Written by: Christy Bailey

An investment of five minutes, a few times per week, can help you heal, change and grow. That's how powerful journal writing can be according to Kathleen Adams, LPC and founder of the Center for Journal Therapy in Denver, CO,

Adams defines journal therapy as the purposeful use of reflective writing to improve mental, physical, emotional and spiritual health.

Journal writing can be especially helpful for caregivers, who are constantly busy meeting someone else's needs. "We can't give from an empty cup," says Adams. By taking some time to release and explore emotions, caregivers can begin to health from the stroke – a step that often is neglected because the focus is on the survivor.

The first step is to choose a computer or pen and paper for your journal. The next step is to write. For some people, morning is the best time. Others prefer to write at night.

Start with a basic "check in" of how you are feeling and what is going on. Then take time to explore concerns that pop up in your writing.

In the beginning, write in five minute blocks, two to three times a week. Over time, try to build up to 15 to 20 minutes.

Give yourself permission to be completely honest about your feelings. You can't deal with any anger, resentment or guilt until you are aware that you feel them.

"Writing in my journal allowed me to express emotions without fear of criticism," says Lori Cavallo, caregiver of her stroke survivor mom. "Once I stopped carrying around my emotions, I became a more patient, giving and loving caregiver."

"When what is coming up in your writing is more distressing that resolving, it's time to talk things through with someone," says Adams. That may mean a support group or a professional counselor or even a good friend.

You can also use writing to provide balance. Note beauty, humor or wisdom that you observe during the day. Write about a colorful sunset or how funny it was when the dog tried to take on the vacuum cleaner. This can help you see beyond your day to day situation.

"There's no right or wrong way to do this," says Adams. With just a notebook and a pen, you can begin to mend from the stroke that changed your life too.

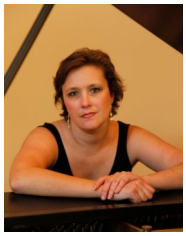
14 Prompts to Jump Start Your Journal

1. I wish that…
2. I want to remember…
3. Today was a [good, frustrating, challenging, perfect, impossible] day.
4. If I had time, I would…
5. What's the most important thing to do?
6. I feel…
7. What do I want?
8. A funny thing happened today.
9. My heart wants to say…
10. What's going on?
11. I need…
12. [Survivor's name] was [describe mood or behavior] today.
13. I'm worried about…
14. Dear God…

By-Kathleen Adams, Center for Journal Therapy
http://www.journaltherapy.com
Adapted from StrokeSmart March/April 2008

Richelle Perkins ~ Benefit Concert for APSFA

Written by: Heidi Ponagai



Richelle "Ricci" Perkins is having a benefit concert on October 8th at Stone Pillar Vineyard in Olathe, Kansas.

From Richelle's Facebook page: "Don't miss the benefit concert in honor the APS Foundation of America, Inc. October 8th at Stone Pillar Vineyard. All proceeds will go to the foundation…..come and find out how one simple blood test can help prevent heart attacks, strokes, recurrent miscarriage….the sister to lupus, APS. At the same time, you will get to enjoy Ricci's last performance in the area before heading to Nashville. Don't miss it!"

Richelle is an APS patient and has been involved with the APSFA since its inception.

This is a wonderful way to show your support for the APSFA as well as enjoy some great music!

For more information: http://ow.ly/6EjHb and http://www.richelleperkins.com

Catastrophic APS Sucks!

Written by: Kitt Ray

My name is Kitt Ray. I was born in Aklavik in the Northwest Territories in Canada. I was educated in England and returned to Canada at 20 years old with my first husband. We lived in western Canada 3 years and then we divorced. I met and married my second husband and we moved to Majorca for 2 years, where I had my son who is now 28 years old. I ended up also divorcing my second husband and raised my son as a single parent until he was 13 when he went to live with his Dad. After this, I went on holiday to St Lucia, loved it, moved down here where I met and married my third husband.

In 1998, I was married and living in St Lucia in the Caribbean, and loving it here. I was 43 years old, had always enjoyed good health, and was living "the good life". In October of that year, I experienced an awful pain in my back and was diagnosed with pneumonia and pleurisy and hospitalized. I was put on antibiotics and muscle relaxants. This happened on the right side a month later, same diagnosis.

I was going through a separation and ultimately a divorce from my third husband, so my stress level was extremely high at this time.

In January of 1999, I was getting dressed and felt a strange pull in my left groin. My left leg immediately started to swell and turn blue! Panicked, a girlfriend drove me to the hospital, and they had me transferred to the posh - translate expensive - hospital. I was immediately put on IV heparin due to DVT, and my blood work was sent to Miami. A short note on the medical situation, St Lucia is a 3rd world country, especially in the medical field!

The diagnosis came back and I was diagnosed with Antiphospholipid Antibody Syndrome - to say I was stunned is an understatement! I was put on warfarin and prednisone with my INR being checked 3 times a week.

In February 1999, I was in the process of being readmitted to hospital in St Lucia with another DVT when I started to experience pain in my right back. I started running a temperature of 105 and was transferred to ICU (a small, extremely hot room, with no fan, oxygen supply was a 100 lb tank, only replaced when it ran out) on IV heparin. I had a pulmonary embolism in my right lung. They tried to drain it with a syringe through my back, then cut a hole into my lung in my side and drained four and a half liters of bloody fluid into a pail. I then received 8 blood transfusions, 4 of whole blood and 4 of plasma.

"In January of 1999, I was getting dressed and felt a strange pull in my left groin. My left leg immediately started to swell and turn blue!"

Needless to say, this was NO FUN!

After 10 days in the ICU I was transferred back to a regular ward. Another note on the hospital situation here, the floors were mopped every couple of days with dirty water, there was only 1 toilet with no seat and you had to supply your own toilet paper, there was 1 cold water pipe sticking out of the wall for a shower for 43 people, sheets and nightclothes had to be provided and changed by friends/family, there was no dosage meter on the IV. I had to monitor and control the pipette myself! And to top it all off, there wasn't a TV or any reading material and I was on COMPLETE bed rest! Did I mention I wasn't having any fun?

At the end of May the doctor called my 74 year old mother in Montreal, Canada and told her to make funeral arrangements as they thought I was going to die! During this time I had multiple other blood clots in my hands, knees, arms and DVTs in both legs.

Thank God for mothers, she came down, closed up my apartment, borrowed money and arranged for the air ambulance, conferred with doctors, packed and stored my stuff, and came up to the hospital twice a day to feed me.

On June 5th 1999, I was taken to the airport by ambulance. They ran out of oxygen. My mom and nurse had to hold the stretcher still as it didn't lock to the wall. The driver picked up a couple of the friends and gave them a ride to a rum shop. My poor mother was totally stressed, at this point I really didn't care what was happening.

The air ambulance complete with doctor, pulmonary nurse, ICU nurse, and all their equipment was waiting. I heard the doctor tell my mom that he didn't think I was going to make it. Then he and I had an argument. I guess because he thought I was going to croak he wanted to put me in a diaper. There was no way I was going to agree to that and he finally gave in.

After arriving at McGill University Hospital, they didn't know what to do with me, no files, X-rays etc had accompanied me. Finally, they stuck me in an isolation room and forgot about me for 12 hours. The room was soundproof and I couldn't get out of bed to ring the call bell.

I was in hospital in Montreal for a month, and while there they did every test they could think of including inserting a Vena Tech filter just below my kidneys, including draining more fluid from my right lung. I was still on complete bed rest and numb from my waist to my knees. I was discharged on oxygen and had to inject low molecular weight heparin (LMWH). Mom and I were living 2 hours north of

(Continued on page 9)

(Continued from page 8)

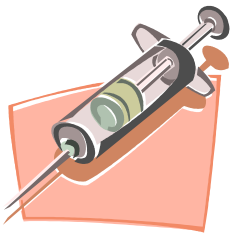
Montreal. My local GP took me off LMWH and put me back on warfarin. I was having my INR drawn 3 or 4 times a week as they could not stabilize me. My INR was regularly over 10.

In October 1999, I moved back to North Battleford, Saskatchewan. I started seeing hematologist Shelia Rutledge-Harding in Saskatoon, she put me back on LMWH. I was also seeing Dr David Cotton, pulmonologist, as my breathing was getting worse and I was still on oxygen. I started working on convincing Dr. Cotton that my lungs needed scraping, a procedure I had researched on the internet.

From January 2002 to October 2002, I was admitted to hospital on various occasions with fever, DVTs, bronchitis, etc. I was still on oxygen. I was identified as having gall stones but the doctors decided not to do anything, as they didn't think I would survive surgery.

In October 2002, I was accepted by San Diego Hospital to have a pulmonary thromboectomy. Dr. Fraser Reubens performed the pulmonary thrombectomy. December 17, I had a cardiac tamponade. They drained it while I was awake, it took over an 1 ½ hours. I screamed the whole time. December 22 I had another tamponade, my blood pressure was down to 60/30 and this time they opened me up again, the last thing I heard before I went under was the anesthesiologist say "Reubens had better get down here, if she croaks we are all in trouble".

I was discharged December 31, 2002, with a pic line in my arm as I had developed an infection. I had to fly on my own to Toronto, I missed my connecting flight due to the weather, got into Saskatoon at midnight, and had to go straight into hospital – happy new year!



In January 2003, the pic line became infected and had to be removed. I was still on antibiotics and oxygen. I came off oxygen in April 2003. I finally had my gall bladder out May 2003.

I had been getting increasingly depressed and in August 2003 went to see psychiatrist, Dr. Mahmood. I was put on strong antidepressants and weekly counseling. I was on Remeron® for almost 4 years.

My hips were becoming increasingly more painful. I moved to Edmonton, Alberta in September 2005. June 2006, I had right hip replaced and then the left hip 6 weeks later. I was told the hips had been damaged by my taking the steroid prednisone.

November 2006, I went to see my GP as I had a bad cough and worsening shortness of breath. She sent me for a CT Scan. I just got home and the doctor called me in a panic and sent an ambulance. They had detected new clots in my lungs. The trauma team at the Royal Alex administered a cocktail of clot busters which didn't work. I was in hospital for 2 weeks.

I was started on 2 needles a day of LMWH twice a day.

Since 2007, I have had various 'issues' – migraines, women's problems, staff infection, high blood pressure, borderline high cholesterol, infections, bronchitis, weeks of feeling ill.

But despite all this medical nightmare, things have got better. I am disabled and can't work. Thank goodness that Alberta has the AISH program (Alberta Income for the Severely Handicapped) which also covers my medical and prescriptions.

I now live in a very small community outside Edmonton, Alberta. Although I can't live there any more I run away from the Canadian winters to St Lucia. I am enjoying living in a small community, and have joined and am very involved in the Rotary Club here in Canada and in St Lucia.

There IS such a thing as life with APS. It's not what I expected to be doing at this point in my life, but it is a definite improvement over the alternative!

(Continued from page 4)

rillation patients is this, "you can stop someone's warfarin with Atrial Fibrillation and it will take almost five years for them to clot. They can have the smallest amount of this drug and probably be ok. However, those with clotting disorders to not have that luxury."

Rebecca Craft Stroud, a member of our APSFA Fan Page, says "Beware of Pradaxa®! My mother is dying in the hospital from bleeding caused from this potent drug. Do your research, and do it thoroughly. Don't be misled by the promises of convenience and the "miracle medical advances" the drug claims to offer."[4]

After hearing this there will be no way I will taking Pradaxa® and if you are currently taking Pradaxa® please discuss these topics with your prescribing doctor. There should be a new and better one on the market in five years that will probably replace Pradaxa®. Dr. Cole did say there is hope that we will have something better than warfarin in the future but this isn't the drug for us.

References:

1. PRADAXA® Official Site. Available at: http://tinyurl.com/3q5pcnt. Last Accessed: October 22, 2011.

2. HIGHLIGHTS OF PRESCRIBING INFORMATION. Available at: http://tinyurl.com/66o9j8p . Last Accessed: October 22, 2011.

3. HIGHLIGHTS OF PRESCRIBING INFORMATION. Available at: http://products.sanofi.us/lovenox/lovenox.pdf. Last Accessed: October 22, 2011.

4. APS Foundation of America, Inc Facebook Fan Page. Available at: http://www.facebook.com/APSFA. Last Accessed: October 22, 2011.

APS Foundation of America
Post Office Box 801
LaCrosse, WI 54602-0801

Phone: 608-782-2626
Fax: 608-782-6569
E-mail: apsfa@apsfa.org
Website: www.apsfa.org
Online Support: www.apsforum.com

FIRST
CLASS
STAMP

Find us online!
www.apsfa.org

APS Foundation of America, Inc.

Our Mission Statement
Founded in June 2005, the APS Foundation of America, Inc. is dedicated to fostering and facilitating joint efforts in the areas of education, support, research, patient services and public awareness of Antiphospholipid Antibody Syndrome in an effective and ethical manner.

Sponsored by: **OPEN**

This time of year is a perfect time to send fresh flowers to your loved ones!

The APS Foundation of America, Inc. has their own flower store!!

http://apsfa.flowerpetal.com

Now when you order flowers at http://apsfa.flowerpetal.com, 12% of each purchase goes to the APS Foundation of America, Inc.

There is no additional fees for delivery—including same day delivery. This means you can save up to $12.95 compared to other online florists. So every purchase puts a smile on many faces—including yours!

Now is a great time to start sending out holiday arrangements!!! So, check out our site and support the APSFA at the same time.

Tell everyone about http://apsfa.flowerpetal.com and help us make a difference.