ANTIPHOSPHO...WHAT?

APS Foundation of America, Inc. Newsletter

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Stella Never Had a Chance

Written by: Kenneth Gunther

Stella was diagnosed with the Antiphospholipid Syndrome (APS) in September of 1994. For the next six months, Stella's tests for LAC and ACL became more out of range with every test. Clinical features of this syndrome are strokes, vision problems, TIA's, seizures, pleural effusion, chorea, CNS problems, coma and death. Stella presented with all of these symptoms and she died on January 23, 1995.

On June 13, 1994, the ER physician notified the doctor about Stella's high aPTT. Another test on June 25th was higher. Stella was not on any blood thinners at this time or ever, even at the time of her death. The doctors had seven months to control her aPTT. During the next several weeks, Stella began to do very poorly. She had blurred vision and lost the ability to even write. On August 5th, she was admitted to the local hospital with seizures.

Stella was having mini strokes. The CT scan on August 8th showed the right side consistent with focal of infarction. No hemorrhage. The MRI findings on August 16th were diffuse ischemic change to moderate severity.

The doctor states Stella has a flare up of a lupus like condition and has the APS syndrome. She was in a coma like condition at this time. The doctor never told me Stella had APS.

She was given 1gm of Solu-medrol a day and in a few days and she did wake up. It was unbelievable. Stella was like she used to be, bright eyed and smiling and talking like she used to. The rheumatologist, in just 8 days, reduced her prednisone down to 10mg a day. She was then transferred to a regular room.

After a few days in this regular room, Stella became very sick once again. The most noticeable thing was her mental change again. She had trouble with seeing and had spasmodic movements, mainly in her arm. She was only on 10mg a day. So, on August 18th, she was back in ICU.

The doctor said she may need anticoagulation based on prednisone response. It's amazing for a doctor to say this and yet not order any blood work. Stella was in the hospital for three more weeks with bouts of confusion and visual problems. Stella did have the ACL test. The rheumatologist notes that Stella's test for ACL is moderately elevated. Records show he did nothing to eliminate the ACL antibody. Even when these tests became much worse, he never made any attempt to treat Stella for this APS. Stella was again having focal seizures on August 28th. Yet on her discharge date, September 4th, the doctor states Cardiolipin IgG was normal at 43.1, IgM 38.3.

Stella was finally discharged on September 4, 1994. Not long after discharge Stella developed CNS symptoms once again, mainly being confused and with vision problems. Stella was still on 10mg of prednisone per day.

Stella was admitted again in October, November and December of 1994 for many problems, mainly seizures, confusion and chorea. An October report states she had a stroke. On admission date, December 4, 1994, Stella had a TIA.

Her next and final admission was December 27, 1994. Stella had not been doing very well for several days. Her mental status decreased. The night of the 27th we were sitting and watching TV with the Christmas tree all trimmed. She started to have trouble completing her sentences. She said she knows what she wants to say but can't say it.

Stella was having problems with her eyes, she said, "The tree is really pretty but I'm having blurred vision and there's spots in my eyes." So I took her to the hospital that night and they admitted her. The next day Stella went into a coma with a stiff neck and positive babinski sign. Since the APS was never treated we are now seeing the development of Catastrophic Antiphospholipid Syndrome. A spinal tap was done and the CSF showed many inflammatory cells with high protein, low sugar, pleocytosis and

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Are You Mapped?

Do you have a pin in our map?? If not, please add it. We are watching in amazement to see the clusters of APS people forming. Our Frappr map is located at: http://www.frappr.com/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 and before long we will be getting ready for Christmas. Summer certainly has gone by fast; way too fast for me! I am not ready for the snow at all.

June was APS awareness month and we did get quite a few press releases and Public Service Announcements (PSAs) about Antiphospholipid Antibody Syndrome (APS) out. This included both paper media and we even hit the airwaves! We have had some great feedback from these PSAs and hope to see more aired in the future. Approximately 3 million people heard our PSAs each time they aired. You can find all of the PSAs located here: http://www.youtube.com/user/APSFA.

Thanks to The Star Radio Group in Fredricksburg, Maryland, the APS Foundation of America, Inc (APSFA) and Antiphospholipid Antibody Syndrome (APS) got some much needed airtime. Matter of fact, not only did we have the PSA's out there, but we also had a half hour of dedicated air time!!

Special thanks go to Deirdre Blake DJ & Sudeep Menachery, MD for making the ½ hour segment possible. The other wobbly voice is me, your President. Let's put it this way, please do not try to do a talk show when you mouth is as dry as the desert with out having mouth spray with you. But, over all, it was a good general overview on APS. I hope everyone will enjoy it. We did manage to have several million listeners hear that show and it did stream live over their stations website.

We do plan on uploading this to YouTube soon. It is too long to upload it as one clip, so it will be broken down at natural points or made into a podcast. We are working on it and will make it publicly available as soon as we can.

Thank You to everyone that helped make this year a success! And a another special thanks to Star Radio Group (especially Bonnie Miller, DJ) for making our maiden voyage onto the airwaves a huge success. Next year will be bigger and better and hitting even more airwaves. We do have raw PSAs that are available for year round use. If you are with a radio station or have a radio station that would be willing to run our PSA, please contact us at apsfa@apsfa.org for the raw file and we will send it directly to the radio station.

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

Sincerely,

Tina Pohlman

President & Founder

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What is the Best Testing Method for Adjusting Warfarin Doses with APS?

Written by: Lori Lambert, Pharm. D Candidate
University of Colorado at Denver, Anschutz Medical Campus
Reviewed by: Al Lodwick, RPh, MA

Because of the antiphospholipid antibody, APSers are different than the typical warfarin patient. A typical warfarin patient can arrive at the clinic, have their finger stuck, and the machine displays a number (hopefully between 2 and 3, in most cases, or 2.5 and 3.5 in some cases). The warfarin dose is either continued or it is adjusted and the patient follows up within the month. With APSers, however, it has been found that even if the machine displays that magical number, the patient is not necessarily safe. In fact, in one third of patients with the antiphospholipid antibody, the INRs given by these finger stick machines have proven unreliable. They may give a value that is too high or sometimes, the machine flashes an error message. To compound the problem further, antibody levels can fluctuate over time. Therefore, the machine may give an accurate reading when the antibody levels are low, but an inaccurate reading when the levels are higher than usual.[1]

What is an APSer to do? Well, there is another test that is used for patients with antiphospholipid syndrome. It is called the chromogenic Factor X (ten) test. It is not a clotting test (i.e. it does not measure the time it takes for blood to clot). Instead, after blood is drawn, the lab spins it down to plasma. Then it is mixed in a machine with something called Russell viper venom.[2] Russell viper is a snake native to India and Southeast Asia that produces venom which causes massive clotting of blood. The clotting factor in the venom directly activates factor X, another clotting factor that is produced in humans by the liver. When factor X becomes activated, color is produced by the machine. The intensity of color provides a reference value which indicates if the dose of warfarin needs to be adjusted. In a recent study of 309 participants, the chromogenic Factor X test was shown to be comparable with INR results. As a result, the chromogenic Factor X test is suggested to be a useful tool for monitoring warfarin in patient populations where the INR is not sufficient. [3] On the downside, the chromogenic Factor X test is more expensive. In addition, it is not as convenient for patients because blood has to be drawn from a vein.

> **"With APSers, ...it has been found that even if the machine displays that magical number, the patient is not necessarily safe."**

In July of 2008, the American College of Chest Physicians (ACCP) published new guidelines that included recommendations for monitoring INRs in people with the antiphospholipid syndrome. The ACCP was founded in 1935 and is the world's largest clinical heart, lung and critical care medical society. It has over 16, 000 members in 100 countries and is comprised of specialists that study the heart and lungs as well as other areas related to the chest. Together, these physicians and other allied health professionals work to promote the prevention and treatment of diseases of the chest through education and research. The new guidelines for monitoring are as follows: [4]

In patients who have a lupus inhibitor (APS) with no additional risk factors (such as Factor V Leiden, pregnancy, smoking, or prolonged sitting) and have always responded to therapy, the recommendation is to achieve a target INR of 2.5 (INR range, 2.0-3.0) [Grade 1A]*

In patients who have had recurrent clots despite being within the desired INR range, the suggestion is to maintain an INR of 3.0 (INR range, 2.5-3.5) [Grade 2C]**

If a patient has additional risk factors for clots, an INR target of 3.0 (INR range, 2.5-3.5) is suggested. [Grade 2 C]**

*Grade 1 recommendations are considered strong and indicate that the benefits do (or do not) outweigh risks, burden, and costs.

**Grade 2 recommendations are referred to as suggestions and imply that individual patient values may lead to different management choices.

For grading quality, randomized controlled trials (RCTs) begin as high-quality evidence (designated by "A"), but quality can decrease to moderate ("B"), or low ("C") for various reasons.[5]

Warfarin monitoring in patients with APS has evolved significantly over the past few years. As researchers gain more knowledge and advancements are made in technology, improvements are being seen in the accuracy and precision of coagulation monitoring. With each method, there are advantages as well as disadvantages. The venipuncture method is the most studied and is usually accurate. The fingerstick check is quick but carries with it the possibility of more inaccuracies. On the other hand, the chromogenic Factor X test is slower but is more accurate in patients with APS. Ultimately, it is up to the patient as to what kind of test is performed. Therefore, if fingerstick checks are not providing adequate results, ask your clinician about the chromogenic Factor X test. With the future of warfarin monitoring on the horizon, it will not be long before an APSer can go to the clinic and complete their test with as much ease as that of a typical warfarin patient.

Credits:

1. Moll S, INR Monitoring in Patients with Antiphospholipid Antibodies with Finger Stick INR Devices. APS Foundation of America, inc. Newsletter (5) Spring 2007.

2. Factor X chromogenic. LabCorp website. Available at: http://www.labcorp.com/datasets/labcorp/html/chapter/mono/cf005600.htm. Accessed July 25 2008.

3. Hirsh J, Guyatt G, Albers G, Harrington R and Holger J. Schünemann. American College of Chest Physicians Evidence-Based Clinical Practice Guidelines (8th Edition) CHEST 2008; 133:71S-109.

4. Guyatt GH, Cook DJ, Jaeschke R, Pauker S, and Holger J. Schünemann. Grades of Recommendation for Antithrombotic Agents: American College of Chest Physicians Evidence-Based Clinical Practice Guidelines (8th Edition) CHEST 2008: 123S–131S.

5. McGlasson DL, Romick BG, Rubal BJ. Comparison of a chromogenic factor X assay with international normalized ration for monitoring oral anticoagulation therapy Blood Coagulation and Fibrinolysis September 2008; 19(6): 513-17.

2nd Annual Venous Disease Coalition Annual Meeting

Surgeon General Announces Call to Action at VDC Meeting

Members of the Venous Disease Coalition (VDC) and the Office of the Surgeon General came together at the VDC Annual Meeting in Washington D.C. on Monday, September 15th. Acting Surgeon General Rear Admiral Steven K. Galson issued "The Surgeon General's Call to Action for the Prevention of Deep Vein Thrombosis and Pulmonary Embolism," which combined affect hundreds of thousands of Americans each year.

Dr. Galson laid out recommendations for the prevention of these two common, yet deadly major public health threats, deep vein thrombosis (DVT) and pulmonary embolism (PE). The Call to Action urges a coordinated, multifaceted plan to reduce the numbers of cases of deep vein thrombosis and pulmonary embolism nationwide. The plan emphasizes the need for:

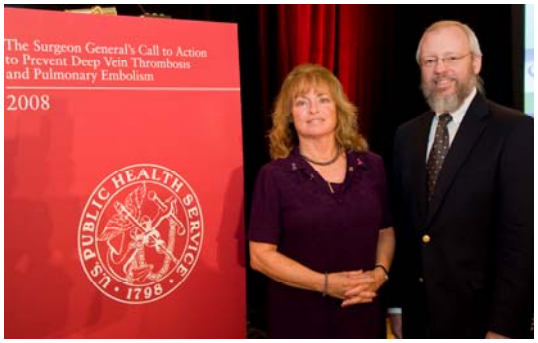
- Increased awareness about deep vein thrombosis and pulmonary embolism.
- Evidence-based practices for deep vein thrombosis.

More research on the causes, prevention, and treatment of deep vein thrombosis.

"Together DVT and PE may be responsible for more than 100,000 deaths each year, but there is reason to believe that the true incidence rate could be significantly higher, as several studies suggest that these diseases are often undiagnosed." said Dr. Galson. "One thing is undeniably clear—DVT and PE are major national public health problems that have dramatic, negative impact on the lives of hundreds of thousands Americans each year."

Watch the video of the Surgeon General's Call to Action at http://www.venousdiseasecoalition.org/events/video_CTA-03.php

In addition to the "The Surgeon General's Call to Action for the Prevention of Deep Vein Thrombosis and Pulmonary Embolism," the VDC conducted its second annual meeting where more than 100 top doctors and members of governmental health agencies and major healthcare professional organizations were in attendance. The VDC outlined plans to respond to the Surgeon General's Call to Action that will create a national public awareness campaign.



Dr. Gale McCarty & Dr. Tom Ortel represented the APSFA at this annual meeting.

"This is a historical and important event," said Samuel Z. Goldhaber, MD, Chair of the VDC and Professor of Medicine at Harvard Medical School. "The Surgeon General's Call to Action will have as much impact on preventing and treating this devastating illness as the Surgeon General's report in the 1960s alerted the public to the dangers of cigarette smoking. Educating the American public about DVT will raise awareness, which will in turn save many lives. We are grateful to Rear Admiral Galson for championing this new government initiative and placing DVT as a top priority on America's health agenda."

The Surgeon General's Call to Action to Prevent Deep Vein Thrombosis and Pulmonary Embolism 2008, is available at http://www.surgeongeneral.gov/library/calls/index.html. To order, contact the NHLBI Health Information Center at 301-592-8573 or at NHLBIInfo@nhlbi.nih.gov.

The **Venous Disease Coalition (VDC)** is a collaborative network of professional and public organizations united by one mission to increase public and health professional awareness of venous disease. The VDC is a public and interdisciplinary consortium dedicated to promoting public and health professional awareness of venous disease.

Source: Venous Disease Coalition. http://www.venousdiseasecoalition.org/events/VDCMeeting_SurgGen.php Last Accessed 9/24/08.

Faces of Antiphospholipid Antibody Syndrome

Written by: Tina Pohlman

The APS Foundation of America, Inc (APSFA) has a special campaign to highlight the impact of APS on individuals with this disease. We need your picture for the APSFA "Faces of APS" Campaign. Our campaign is intended to increase awareness of APS.

The Faces of APS shows the many faces of this unpredictable illness and exactly how invisible APS is to the public, our family and friends. Antiphospholipid Antibody Syndrome (APS) receives far less attention and funding than other illnesses yet more and more people are being diagnosed with APS. There are currently only 144 faces on the site and anyone with APS is welcome to add their picture here: http://www.frappr.com/apsfa/photos. The best part, you ***don't*** need a scanner or digital camera!

We are encouraging you to include a short paragraph that describes how APS has affected your life and/or the life of your family.

You can also add the "Faces of APS" slideshow to your website, blog or even your MySpace page to help bring awareness to APS.

Having problems getting you picture on the slide show after you have registered, email us your picture at staff@apsfa.org and we will put it on the page for you.

Potential Drug Interactions Between Antibiotics and Warfarin

Written by: Gretchen F. Kunze, Pharm. D
University of Colorado Health Sciences Center
Reviewed by: Al Lodwick, RPh, MA

While I was a pharmacy student at the University of Colorado, I had the opportunity to do one of my rotations in an anticoagulation clinic. During my time there, I became very aware of how difficult and frustrating it can be to stabilize a patient's INR in the appropriate therapeutic range. There are many things that have to be taken into consideration when choosing the correct dosage of warfarin including diet, activity level, disease states, and possible drug interactions. There are many drugs that have the potential to interact with warfarin and cause either an increase or decrease in the INR. If these interactions are not managed appropriately, adverse outcomes can occur and even prove to be fatal.

Sometimes it is difficult to avoid such an interaction when both therapies are needed. An example of this is when patients become ill and are prescribed an antibiotic. Many of the antibiotics are known to interact with warfarin and can cause either an increase or a decrease in the INR (see Table 1). The patient may feel like they need to stop taking their warfarin or not take the antibiotic to avoid this potential interaction. Because both of these medications are important, however, taking the combination can be done, but careful monitoring as well as adjustment of the warfarin dosage is essential in managing any interaction that may take place.

Although a lot of antibiotics can interact with warfarin, some of them interact stronger than others and can cause a more significant change in INR. These interactions can occur immediately or may be delayed depending on the antibiotic given. In addition, the effects of some antibiotics can continue days to weeks after the antibiotic has been stopped. Therefore, an interaction with warfarin can also occur after the antibiotic has been discontinued. An INR should be checked within 3 to 5 days at the very latest after starting an antibiotic, and it may also need to be checked days after the antibiotic course has been completed [2,5].

In 1997, there was a case report of a patient that experienced the consequences of the interaction between warfarin and the antibiotic clarithromycin. Five months after starting warfarin therapy for atrial fibrillation, the patient's INR finally stabilized in the therapeutic range of 2 to 3. Ten days after the last INR was checked, the patient was started on a 14 day course of clarithromycin for bronchitis. An INR was not checked until 3 days after the 2 weeks of antibiotic treatment. At that time, the patient's INR had skyrocketed to 16.8! The patient was admitted to the hospital immediately and given vitamin K to reverse the high INR[4]. This case is an example of what can happen if the INR is not monitored early and frequently after starting antibiotic therapy.

There are a few antibiotics that interact with warfarin that can cause a decrease in INR, increasing the chances of a clot to form. A 39-year old man developed an infection in his knee shortly after undergoing arthroscopic knee surgery. During examination, he was also found to have a deep vein thrombosis (DVT) in his lower leg. After initial treatment in the hospital, the patient was sent home on the antibiotic cefazolin for his infection as well as warfarin for his blood clot. For the first month, the patient's INR was stabilized on an average warfarin dose of 32 mg/week. The patient's antibiotic therapy was changed, however, and he started taking nafcillin. Over the next 3 weeks, the patient's INR dropped below the therapeutic level, and his warfarin dose had to be increased to a total of 88 mg/week in order to bring his INR up. The interaction between nafcillin and warfarin caused a 3 fold increase in the amount of warfarin that was required to achieve a therapeutic INR. After nafcillin was stopped, his warfarin requirements slowly declined over the next several weeks[5]. Other case reports have noted a 2 to 5-fold increase needed to maintain therapeutic INR's while taking nafcillin[5].

It is extremely important that you talk to your physician whenever a medication, including an antibiotic, is either added or removed from your drug regimen. This ensures that appropriate measures can be taken to avoid any possible adverse reactions that may occur due to an interaction with warfarin. Patients should always be reminded of the signs and symptoms of bleeding as well as clotting (see Table 2). Just because a medication may interact with warfarin does not mean that the combination cannot be taken safely. INR's should be checked early and frequently and it may be necessary to hold warfarin, decrease the dosage, or increase the dosage (sometimes considerably) to maintain a therapeutic INR.

Table 1: Antibiotics that may interact with warfarin and cause a change in INR

Antibiotics that can cause an **increase** in INR	Antibiotics that can cause a **decrease** in INR
Bactrim®	Nafcillin®
Levofloxacin (Levaquin®)	Dicloxacillin®
Ciprofloxacin (Cipro®)	Rifampin®
Moxifloxacin (Avelox®)	Rifabutin
Azithromycin (Zpak®)	
Clarithromycin (Biaxin®)	
Erythromycin	
Doxycycline	
Tetracycline	
Minocycline	
Amoxicillin	
Augmentin®	
Metronidazole (Flagyl®)	
Fluconazole (Diflucan®)	

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Table 2: Signs and Symptoms of Bleeding and Clotting

Signs and Symptoms of bleeding (increased INR)	Signs and Symptoms of clotting (decreased INR)
Blood in urine or stool Gum or nose bleeds Excessive bruising	Pain, redness, and swelling in a limb, chest pain, shortness of breath, changes in mental status, sudden weakness or numbness in extremities, difficulty finding words or understanding speech

References:

1. www.warfarinfo.com
2. Glasheen JJ. Fugit RV. Prochazka AV. The risk of overanticoagulation with antibiotic use in outpatients on stable warfarin regimens. Journal of General Internal Medicine. 20(7):653-6, 2005 Jul.
3. Vadlamudi RS. Smalligan RD. Ismail HM. Interaction between warfarin and levofloxacin. Southern Medical Journal. 100 (7):720-4, 2007 Jul.
4. Recker MW. Kier KL. Potential interaction between clarithromycin and warfarin. Annals of Pharmacotherapy. 31(9):996-8, 1997 Sep.
5. Kim KY. Frey RJ. Epplen K. Foruhari F. Interaction between warfarin and nafcillin: case report and review of the literature. Pharmacotherapy. 27(10):1467-70, 2007 Oct.patient has to balance the wisdom of these guidelines (which are general guidelines and not mandates applicable to ALL patients) with the needs of his/her patient to find the best answer. Physicians are directed to please read these References to understand the caveats and critiques of systematic reviews/meta-analyses of studies.

How To Be a Good Patient

Submitted by: Tina Pohlman

How can you help your doctor help you? It is very simple—keep records, keep records, keep records. When you are battling an autoimmune disease (or two or even seven for that matter), the amount of information relating to your illness and its treatment can be staggering. Every doctor that you see or medical test that you have done adds one more piece to your complex medical jigsaw puzzle. Unfortunately, it is very unlikely that any one doctor has access to all pieces of that puzzle at one time. But what if he did?

Imagine how much more your doctor could offer you if he had every bit of pertinent information about your case before him in one organized place. It would be like having "The Book of You". By simply thumbing through it, he could review your medications, the results of past medical tests, the outcomes of procedures or surgeries you have had done, and much more. With this wealth of knowledge about your individual situation, your doctor may see patterns that he normally wouldn't or notice problems with your treatment or underlying issues that were hidden before. All of this could change the course of your treatment in a small or very large way.

So, clearly it would be invaluable if there was such a thing as "The Book of You". Well, there can be and you can create it!

Here are some suggestions on how to create your personal "book":

Hunt and Gather: Starting today, I want you to become a hunter/gatherer with a mission – to hunt down and gather as much documentation relating to your illness as possible. This includes results from lab tests, doctor's notes, pathology reports, and even photographs. Anything that is relevant to the diagnosis, treatment or progression of your disease is fair game.

You may already have much of this documentation stuffed in a drawer or hidden in a filing cabinet somewhere. If so, find it and dig it out. If you don't, this will require a little bit more work and time. Start by making a list of all of the physicians that you have seen who have been involved in diagnosing or treating you. If possible, find their current office telephone numbers and put in a request for all of your medical records. If you haven't already, you will probably have to sign a form before they will release your records and some offices will charge a processing fee.

I recognize that obtaining all of your records may not be the easiest task in the world, especially if you have been on this journey with autoimmunity for many years. Memories fade, doctors move, records are destroyed; but with a little concerted effort, you will be amazed at what you can find. If you hit a few brick walls, don't be discouraged. Simply find as many records as you can.

Organize: Once you have gathered all of the pertinent documentation, it is time to make it useful. No matter how much paperwork you have, it is not going to offer you any benefits if it is in one big messy pile in a drawer. It needs to be organized in a way that makes the information easily accessible. This can be done in several different ways and depends upon the amount of documentation you have to organize as well as its content.

Some people prefer keeping their records in a filing cabinet, but I favor using binders, even if it takes several of them. This way the information is portable, allowing you to easily bring your records to each doctor's appointment.

As to how you organize the information within the binders, that is more of an individual decision. If you have only a few papers, you may want to simply place them in chronological order. However, if you have a lot to organize, or have a complicated case, you will probably want to subdivide the information. Using some cheap dividers you can break up your binder into many different categories, including type of illness (if you have multiple diseases), subspecialty (example: hematology, neurology, endocrinology, nephrology, etc.), or physicians name. No matter how you organize your binder it is best to keep the information in chronological order within each category.

Create: After collecting and organizing all of the information that you can find from your doctors, there is one more step to becoming a good patient. It involves creating a journal

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no bacteria of any type were ever found.

On the 4th day of her coma, December 29th, all these tests were back showing high numbers for ACL, aPTT and LAC. She was getting antibiotics at this time. The antibiotics were onboard so steroids could have been given at the same time. The rheumatologist never made any attempt at any time to treat Stella for APS or possible SLE.

Even while in the coma with all the antibiotics she was getting, Stella continued to have spiking fevers. Yes, it was her immune system and Stella needed high doses of steroids, not three weeks from now, but immediately in order to have any chance of survival. Stella did not pass away because of any infection.

Truly, Stella never had a chance.

On the January 10, 1995, the rheumatologist notes the LAC of 408 and ACL of 55.8 and still no heroic measures were taken to eliminate the APS antibody. On January 18th, I called doctor's office and asked him to meet me in Stella's room that evening. I said to him that Stella has been in a coma for three weeks now and impressed upon him that I think lupus put her in this condition. He said, "Okay, I will start treating her for lupus." This is why, and I think the only reason, Stella ever received high dose steroids.

After I got the rheumatologist to give her high doses of Solu-medrol the night of January 19th, I saw a difference in Stella. For the first time in three weeks of being in a coma, Stella heard my voice. As I had been doing for three weeks, I leaned over and said to Stella I was praying for her. She began to cry with heavy tears coming from her eyes. I was startled to see this. I knew the high dose steroids were working. Stella needed this three weeks ago but it was too late for a complete recovery.

To confirm my suspicion, I called the NIH in Washington, D.C., and they gave me some names of rheumatologists who would tell me what happened to Stella. He looked at me and this is what he said, "This Antiphospholipid Syndrome is what most likely killed your wife." This doctor asked why they didn't treat her for APS.

I have done my homework. I have thoroughly researched the medical journals, conversed with medical authorities and have come to the conclusion that all of the records will substantiate that my wife, Stella, would most likely be alive today if her condition had been properly treated with appropriate medication.

A complicated case? Not at all.

This content is abridged from Antiphospholipid-Syndrome.com.

New! APS & Lupus Clinic Opened in DC

One of the APSFA Medical Advisory Board members, Gale A. McCarty, MD, FACP, FACR, has opened a dedicated Center for Lupus and Antiphospholipid Antibody Syndrome (APS) at 2440 M St NW, Suite 510, Washington DC 20037, with advanced autoantibody testing and onsite coagulometry. With electronic health records and specialized educational services/patient informatics, the Center caters to patients who have email but can serve those who do not. She will maintain her teaching involvement with area academic rheumatology units/trainee education, clinical/outcomes research in SLE and APS, and offer infusion therapy and clinical trials.

Office phone number for appointments is 202-466-4774, fax is 202-466-4776, and her website/patient portals are currently under construction.

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or log of your experience and can be incredibly useful to your physician and to yourself.

This does not need to be a book of literature, but can simply be a collection of lists. The content of these lists should include the following:

Medications: Make a list of all of your current medications, the dosages, as well as how and when you take them (example: aspirin, 81 mg, taken by mouth 1x per day). If your doctor switches prescriptions or dosages, jot down the date and the change in your journal. I would highly recommend keeping the current list of medications at the top of all of your medical records, because almost every doctor and nurse will ask you for this information. If you want to be very proactive, you can even keep copies of this list and hand them to your doctor at each visit. If possible, it would also be helpful to compile a list of your past medications, the dates you took them, any side effects that you may have had, as well as the date and the reason for their discontinuation.

Major events: Keep a log of any major events that may affect your disease or its presentation. If you have an accident, surgery, or even a highly emotional event, write down the date and a brief description of the event. The memory may be so vivid now that you think you will never forget the date or the event's effect on you, but ten years from now memory of the details might fade.

Symptoms: Make a list of all of your current symptoms. If you like you can even keep a symptoms journal, jotting down the date, time, description, and severity of the symptom. Over time you may find very informative patterns that would otherwise be missed, especially when you have a list of medications and major events to compare it to.

In summary, becoming a good patient means becoming an expert on you and your own individual medical history. By either knowing the relevant information or where to find it, you can give your doctor invaluable tools to facilitate your treatment. However, while having these medical records is undeniably useful, the process of finding and organizing them may sound daunting. If this is the case, please don't be distressed. You can start small and start from today. If you don't want to find old records, simply request them from your doctors from now on. If tracking your symptoms and major events sounds overwhelming, begin by making a current list of your medications. To be a good patient it is not necessary to be perfect, only to be proactive. This is your body and your health and you can be an integral part of your own medical treatment.

APSFA Needs Your Stories and Articles!

Written by: Heidi Ponagai

We strive to bring you the best newsletter that we can each quarter. In order to do so, we need patient stories and stories of interest from APS patients and their loved ones.

Topics can be from how APS affects you, poems you have written, your favorite hobby, tip and tricks that help you get through your day, to your favorite recipe. We are also taking book reviews of publications listed on our suggested reading page at: www.apsfa.org/publications.htm

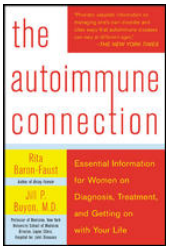
Please follow our current guidelines when submitting an article:

- Send your story/article to articles@apsfa.org
- Patient stories and most articles should be approx 500-750 words long
- Articles should be written at a 5th-8th grade reading level
- Please try to include a picture when submitting a patient story
- Patient stories should read like an autobiography—generally from diagnosis to present time, but it doesn't have to

If you have an idea not listed here and are not sure if it would be appropriate? Drop us an email at articles@apsfa.org.

Book Review ~ *"The Autoimmune Connection"*

Written by: Tina Pohlman



The Autoimmune Connection (Paperback) by Baron-Faust, Rita, and Jill P. Buyon, M.D.; Published in 2004 by: McGraw-Hill (March, 2004); ISBN-10: 0071433155; ISBN-13: 978-0071433150

The Autoimmune Connection starts out with a short tutorial on the immune system, including how it is supposed to work as well as how it may break down in cases of autoimmunity. There is also a brief theories relating to why the sufferers of many autoimmune diseases are more prevalently women.

The real book then begins tackling over twenty individual autoimmune diseases that commonly affect women. Each illness is approached in mostly the same format—an explanation is followed by a description of the possible causes and symptoms of the illness, the path to a diagnosis, the treatments that are currently available as well as those that may be offered in the future. There are also sections explaining how women are particularly affected by each illness at different stages of their lives. Scattered throughout each chapter are informative vignettes from women who are on the forefront of the autoimmunity battle, either because they are fighting an illness themselves or because they are family members of someone who is.

The last chapter investigates and recommends how a patient can best approach our medical system. Included is a very useful section on choosing the appropriate doctor, explaining which medical specialty is best suited for the treatment and management of each autoimmune disease. The authors also explain how to be the best patient one can be, suggesting several helpful techniques on becoming proactive in one's own healthcare.

The Autoimmune Connection closes with a brief afterward by Dr. Denise L. Faustman, a fellow survivor of autoimmunity. She provides an encouraging glimpse into the future evolution of the perceptions and medical treatments of autoimmune diseases as well as her hopes for this progression.

Finally, appendices are also provided, listing the contact information for support groups as well as other books recommended by the authors.

Pros:

A Female Focus: While much of the content is pertinent to both men and women, there is a consistent focus on how autoimmunity specifically affects women. This is the only book that I know of that explores the evolvement of so many autoimmune diseases through each stage of a woman's life—from puberty through pregnancy, menopause and the life beyond.

Perceiving Autoimmunity In A New Light: Much of this book strives to find the connections between the many autoimmune diseases, viewing them as possibly one illness with many different presentations. I found this approach to be very thought-provoking and unique. Maybe the authors have stumbled upon a key to solving the puzzle of autoimmunity and we should all be focusing on what those with autoimmune illnesses share instead of what they don't.

Cons:

Convoluted Path to the Truth: If you are looking for a simplistic exploration of autoimmune illnesses, you may want to steer clear of *The Autoimmune Connection*. You will be forced to read a lot about immunology and genetics, and may sometimes feel like you are slogging through medical jargon. While I respect the authors intent to provide depth and completeness to their writing, I do feel that they may have lost sight of their prospective audience, the lay person – you and me. By getting bogged down in terminology and technical matters, they are running the risk of frustrating and scaring off a good deal of readers. By using more lay person language and examples, I believe that they would have reached a wider audience without sacrificing the information.

The Verdict:

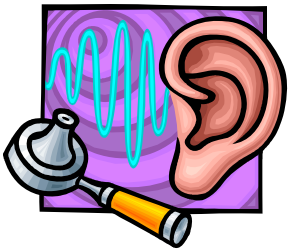
The Autoimmune Connection is undeniably full of helpful information that comes directly from some of the foremost authorities on autoimmune illnesses. The range and scope of this book is impressive. The women of autoimmunity are the centerpiece of this story from beginning to end. If you are one of these women, I would recommend adding this book to your shelves, even if you simply use it as a medical reference from time to time. I have personally dubbed it a mini dictionary on autoimmune illnesses.

★★★★☆

Early Diagnosis Is Important ~ Terry's Story

Written by: Terry Fuhr

My name is Terry. I'm 48 years old and live in Shawnee, Kansas.



I have been diagnosed with: Antiphospholipid Antibody Syndrome (APS), Systemic Lupus Erythematosus with (Raynaud's and Sjögren's syndromes), Secondary Fibromyalgia, Autoimmune Inner Ear Disease (AIED) with sensorial/progressive hearing loss, chronic tinnitus, Hyperacusis, osteoporosis, osteoarthritis, Vitamin D deficiency and a depressive disorder.

10 yrs ago, I had 3 DVTs and nearly lost my foot. An emergency angiogram, angioplasty and stent placement saved my life. I was in intensive care for a week on Urokinase therapy to dissolve the clots. I literally saw death and prayed with the chaplain. I was told that since I was so young that the only explanation could be that they were caused from smoking.

In late 1999 the stent failed as I was taken off warfarin therapy and they had to do another emergency angioplasty and open the stent with a balloon. I was then placed back on warfarin for the remainder of my life. My INR range has been set to 3-3.5.

Over the next 3 yrs I lost all my teeth (regardless of all the root canals to save them) with no explanation, I went thru early menopause taking away my chance of ever having a daughter. Thankfully, God has given me two beautiful daughter-in-laws and three perfect grandchildren. So, I am blessed. I had my gall bladder removed and began having issues with my eyes and throat all with no explanations. I became addicted to cough drops trying to keep my throat moistened. I went from having perfect vision to needing bi-focal eyeglasses and putting drops in my eyes 4 times a day.

I have had hearing problems since I was about 20 but was always able to function normally with the help of a hearing aid. In February of 2007, I began having daily headaches. I became disoriented, confused, unable to sleep, and developed a rash. I was frightened, sad and my pain began to control my life.

I went for a new hearing evaluation to see how bad things really were. I was not functioning very well at work and was beginning to have problems. I was referred to an ENT specialist. I was very fortunate this doctor picked up on the blood clotting problems and ordered the appropriate blood work to confirm his suspicion of APS. He explained how the autoimmune disease was robbing me of my hearing. He then referred me to a Rheumatologist for further evaluation. At this time I was losing time from work, hardly able to walk, and I was afraid to sleep for fear I would not wake up. I was also having a hard time and could not communicate clearly and it was frustrating for my coworkers and leaders.

I began to research APS while waiting for new test results. I read how similar all my symptoms were and began questioning my doctors and my family. After digging into some blood lines I found that there is Lupus in my family's history. One of my cousins was still battling with Lupus. I also found atherosclerosis on both sides of my family with no real explanation for its progression. I began to recognize very clearly what was going on and took my findings back to all my doctor appointments.

After 10 years of misdiagnosis, I was finally diagnosed with Systemic Lupus Erythematosus and Fibromyalgia along with the Antiphospholipid Antibody Syndrome. Long story short - after reduced hours and responsibilities at my job, I became unable to perform my required duties and ultimately ended up on short-term disability. I went from working 5-6 days a week, 12 hours a day to not being able to work at all.

I am now on a number of medications: warfarin, azathioprine, amitriptyline, pantoprazole, Vitamin D, simvastatin, metoprolol, prednisone, 3 types pain pills as needed, eye drops and steroid creams. The side affects of some of the meds I'm on is enough to depress and make you paranoid. It can make you feel like a ticking "time bomb".

My world is like a "bubble". I rely on closed captioning, email or lip reading for the majority of my communication. I used to love music and pour my soul into it . I am so deeply saddened that I cannot enjoy this past time any longer. I still hear sounds but cannot understand what is being said.

I am reminded to take meds and mail this or that etc with all my notes and post it's around the house. I forget things so easily now. I have been robbed of my career, life and family dreams.

My pain, swelling and fatigue have no boundaries and I hide it as much as I can. I am in a pleurisy flare now as I type this. My two pages of symptoms are overwhelming. I depend on my husband to be my primary communicator and caregiver. This has all weighed so heavy on him yet he does not complain about it. His unconditional love is very moving. My two sons whom I love dearly share and converse about our happy times together as a family. I cherish those conversations and moments so very much. I mourn for my old life and my old body. If I had been diagnosed earlier I may still be able to hear today. It is so critical that awareness is campaigned across the country. Every doctor, nurse, hospital, clinic, school and dentist needs to be aware of our silent killers and their symptoms.

We live in a society where pain and illness are recognized and sympathized if they are visual.

The blood tests are the easy part. I plan to do whatever I can to spread awareness about all of the diseases that I have. If I can save one life or one person's hearing, it will be worth it. Maybe this is my destiny and where my faith has led me - my purpose for that 2nd chance in life. I am keeping my head up and my faith strong and am always eager to share my story to help educate others.

With my family and my Savior as my strength, I cherish each day.

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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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