# ANTIPHOSPHO...WHAT?

APS Foundation of America, Inc. Newsletter

Volume 26 Fall/Winter 2012


*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!*

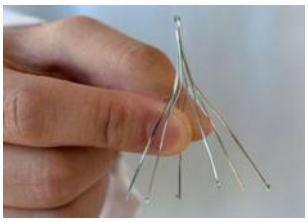
## IVC Filters In APS


**Written by: Michael D. Lockshin, MD**

**The Barbara Volcker Center for Women and Rheumatic Diseases, Hospital for Special Surgery, New York, New York**

**Professor of Medicine and Obstetrics-Gynecology, Weill-Cornell Medical College**


Should IVC filters be placed in patients with antiphospholipid syndrome (APS)? Is it safe to place an IVC filter in a patient with APS? These questions come up often. Surprisingly, however, the questions have not been well studied, so most information comes from anecdotes published as case reports and from personal experience. For those interested, we reviewed the topic, among others, in a medical textbook a few years ago.[1]



***What is an IVC filter?***

"IVC" stands for inferior vena cava, the large vein that collects all blood flowing from the abdomen and legs to the heart. (The SVC, or superior vena cava, collects blood that flows from the head, arms, and chest to the heart.) A blood clot from the legs or abdomen that breaks free will go to the lungs through the IVC to become a pulmonary embolus, which can be lethal.

An IVC filter is an umbrella-like device, inserted (closed) through a small tube inserted through a leg or arm or neck vein into the IVC. Once in place it is opened, ribs pointing down, and it stays in place because little hooks on the ribs attach to the IVC wall. Its purpose is to catch clots before they go to the lungs.

There are many kinds of IVC filters. A few are made of metal; because magnetic fields in MRI scanners can move metal filters, people with this kind of filter cannot have MRI scans done. Most currently used IVC filters, however, are not magnetic, so MRIs can be done. Some filters are temporary, that is, they can be removed after one or two weeks, by threading something like a fishhook into the vein to pull the filter out. Temporary filters are usually used in high risk situations in which clotting is a temporary risk, such as orthopedic or gynecologic surgery. Other filters are meant to stay in place permanently.

***What are the risks of an IVC filter?***

All interventional procedures—placement of an IVC filter is one—have risks. The risks are low, but include risks of dye given to see the filter as it is being placed, which can cause allergic reactions or kidney problems, perforation of a blood vessel, dislodgement of a clot during the process, breakage or migration of the filter, and clots forming on top of the filter. All of these circumstances can require major surgery, sometimes done on an emergency basis.

***What about APS patients?***

In APS patients, the temporary, retrievable filters generally cannot be used because the clotting risk continues. In my own experience, permanent filters in APS patients—despite continued anticoagulation—often fill up from below. In this case the IVC becomes completely blocked, resulting in continued, profound and very uncomfortable swelling of the legs and abdomen. In addition, sometimes clots form *above* the

*(Continued on page 3)*

## Click Below to Follow APSFA

## Patient Stories & Articles Needed!

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

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

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

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

Without your help our newsletter cannot be a success!

**Inside this issue:**

## Letter from the President

*Winter is fast approaching me, with a 30ºF plus degree temperature drop. The squirrels are fat and furry so I think we are in for a cold winter then again, I said that last year and we really had a warm winter here.*

*I must apologize for not having a newsletter last quarter. Due to my health, summer was shot due to Lupus flare, and lack of articles to produce our usual quality newsletter, I decided to skip it to spare you a newsletter of filler. We read enough filler elsewhere. This newsletter does have some articles of interest to the APS population and to quality standard.*

*Café Press is growing again. We are adding more and more products every day. 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 . As Facebook flops, my New Year's prediction, we will be relying solely on this e-Newletter list, so please sign up. As we work more with APS ACTION more APS news will be coming out through research that was sponsored or co-sponsored by the APSFA.*

*We liked how the tree went last year so we will continuing doing our Giving Tree like that again. 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 (oddly it isn't the APS causing the problems right now, it is the Lupus), my numerous doctor appointments, lab draws, and other responsibilities in my personal life I have just been drained. 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*

## APSFA Board of Directors



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.**

# Life is a Celebration

**Written by: Heather Andrews**

Out of the blue- my leg and thigh were triple the size it should be. Little did I know the journey this incident would take me on.

Twenty-three years ago, when I was 41 I was diagnosed with a blood clot out of nowhere. I was active, thin, never smoked, athletic - it didn't make sense. After more blood clots, we went all over the country to try to find answers. Five years later, I began to lose kidney function and that is where we found our incredible miracle of a doctor. He listened and put the pieces together.

**Steve Litt and his wife, Louise.**

My mother died when she was 36 years old. She had a stillborn baby and I was born a month early at only four pounds. My mother was always sick and died when I was seven years old. The only thing I was told was that she died of uremic poisoning. When we explained the family history, our doctor went- "BINGO"- I know why you are getting recurring blood clots- I would bet my life on it that you have APS." Of course, we said, "What?????"

I am now 64 years old- it has been an incredible ride celebrating life and living with APS. By the time it was discovered my veins had already been severely compromised. An outcome of that is that I get extremely painful ulcerated sores on my lower limbs and feet. But I have not allowed it to stop me for a minute.

A blood clot went to my heart which of course, meant that I had a heart attack. The same episode caused my right lung to collapse. It was a close call but I am a fighter and I came back strong.

The most recent event has "altered" life to a "new normal." I had a stroke, which affected the executive suite of my brain. The doctor insisted I stop working immediately – which I had to do kicking and screaming. The stroke also affected my field of vision and I can no longer drive. But that has not kept me down! I work out three times a week at a fitness center by our home and volunteer twice a week at a near by hospital.

With all of this I feel so blessed to be celebrating life with my lovely wife of 40 years. We have two beautiful children with incredible spouses and we are truly blessed to have four delightful grandchildren that bring such sparkle and joy to our lives.

I have a new norm that is bringing me so many treasures along with amazing doctors that are in sync to keep me as active and healthy as possible. I wake up everyday and go to bed every night so grateful to our incredible kidney specialist that had the wisdom, experience, and incredible listening skills to guide my wife and me on this very special journey. My grandchildren call me "Grandpa Gopher" and when they run into my arms and give me hugs and kisses I know that I am the wealthiest and healthiest man alive.

Life is an incredible celebration.

*(Continued from page 1)*

filter, that is, on the "north" side, and those clots can themselves break free and become pulmonary emboli. In other words, it is possible that an IVC filter can increase the risk of pulmonary embolus rather than protect against it. Finally, emergency surgery for a complication, such as a ruptured vein, is very difficult and very risky in APS patients.

***Bottom line.***

The complications are rare. Many patients have received IVC filters with no problem. However, dealing with the complications is difficult and dangerous. For these reasons—recognizing that some circumstances are life-threatening and leave no choice—when asked the question, I recommend that IVC filters *not* be used in APS patients if at all possible.

Notes:

1. Gordon J, Goldenberg D, Erkan D, Lockshin MD, Difficult Clinical Situations in the Antiphospholipid Syndrome. In: Ronald A. Asherson, editor: Handbook of Systemic Autoimmune Diseases, Vol 10, Antiphospholipid Syndrome in Systemic Autoimmune Diseases, Ricard Cervera, Joan Carles Reverter and Munther Khamashta. The Netherlands: Elsevier, 2009, pp. 215 – 234. ISBN: 978-0-444-53169-8

# Different Ways To Donate To The APSFA This Coming Holiday Season

**Written by: Heidi Ponagai**


The 2012 Holiday season is upon us. Boy, did it get here quickly! Now is the perfect time to start thinking about where your holiday charity donations are going this year. This page is going to be dedicated to the many different ways you can donate to the APS Foundation of America, Inc. during the holiday season as well as the rest of the year.

## Donation Ideas

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

- We accept monetary donations in honor or in memory of family, friends, or loved ones.

- You can print a donation sheet from our website, or send us donations via PayPal online. We accept personal checks and money orders and credit card donations through PayPal.
- On our website we have APS informational booklets, burgundy ribbon, infant loss, and APSFA lapel 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, & $25 per month for one year. These can be done by PayPal, or by check if you wish. Contact us for more details.
- Our Flowerpetal site is open year round. 12% of all sales goes to the APSFA and shipping is always free!
- You can also do your online shopping through our Amazon link or using GoodShop.
- In our CafePress store we have many holiday items: cards, ornaments, stockings, etc.

All donations made to the APSFA are tax deductible and we send out receipts for all donations we receive for tax purposes. Please see our website for more information on making donations to the APSFA.

www.apsfa.org/donate.htm

Please be sure to have all donations for 2012 post dated by 12/31/12.

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

## APSFA Online Giving Tree

Our "Giving Tree" was a great success last year, so we're bringing it back this year! Our tree will be "planted" by the time this newsletter goes to print, so please see our website for more details and help us decorate our tree!

The "Giving Tree" will work just like last year, with each ornament on and package under the tree representing a donation. All "Giving Tree" donations are tax deductible.

There will be buttons for making special "Giving Tree" ornament donations on the site. Ornaments will come in different shapes and colors to represent different donation denominations, and just like last year, names (first initial, last name) will be printed underneath the tree and the ornaments will be added to the tree.

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

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

Information about our "Giving Tree" can be found on our website at:

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

## The APSFA CafePress Online Store

We have a wide selection of APSFA, APS, DVT, Lupus, Infant Loss, FVL, and thrombosis gear located on our CafePress online store.

With every item purchased, the APSFA receives a small donation. 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, sweatshirts, teddy bears, aprons, mugs, cell phone cases, and stickers, just to name a few. We also sell a lot of our APS log books which are a great tool for any APS patient. They are great to bring to appointments because all the information you need is right there.

As has been our tradition since 2005, we have our exclusive APSFA Keepsake ornament. We have picked a snowflake to adorn our ornaments because all snowflakes are different, just like every APS patient is different. The ornaments are $8.99 each and are made of porcelain. We have made this design available on other items as well!

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

# Antiphospholipid Syndrome Alliance for Clinical Trials and International Networking (APS ACTION) Update #I

**Written by: JoAnn Vega, CCRC (APS ACTION Lead Coordinator)**

APS ACTION is the first ever international research network that has been created specifically to design and conduct well-designed, large -scale, multi-center clinical trials in persistently antiphospholipid antibody (aPL)-positive patients. Please refer to APS Foundation of America's 24th Newsletter (Winter/Spring 2012) for the background information.

The 3rd Annual APS ACTION Summit took place on November 8 and 9, 2012 in Washington, D.C. The summit was an overview of how far we have come in the last two years. The highlights of the Summit were:

- *APS ACTION International Clinical Database and Repository* currently has nine centers with Institutional Board Approvals (IRB) (Table 1), and 20 patients have been enrolled thus far.
    - ◊ The purpose of this study is to design and maintain a secure, web-based clinical database and repository of persistently aPL-positive patients so that the natural course of these patients can be followed over 10 years. The APS ACTION Registry will also help us study large groups of aPL-positive patients in a more organized way; this will allow for a better assessment of clinical characteristics and which aPL-positive patients are at increased risk for clinical problems.

**Table 1: Centers Currently Recruiting for the APS ACTION International Clinical Database and Repository**

| Center Name | Investigator(s) |
|---|---|
| Hospital for Special Surgery, New York, NY, USA | Doruk Erkan<br>Jane Salmon<br>Michael Lockshin |
| University of Brescia, Brescia, Italy Europe | Laura Andreoli<br>Angela Tincani |
| University of Texas Medical Branch, Galveston, TX, USA | Silvia Pierangeli |
| University of Rio de Janeiro, Rio de Janeiro, Brazil South America | Guilherme de Jesus<br>Roger Levy |
| University of Athens, Athens, Greece Europe | Maria Tektonidou |
| University of Milan, Milan, Italy Europe | Pierluigi Meroni<br>Cecilia B. Chigizola |
| University Hospital, Padova, Italy Europe | Vittorio Pengo<br>Allessandro Banzato |
| University of Sao Paulo, Sao Paulo, Brazil South America | Danieli Oliveira de Andrade |
| University of Utah, Salt lake City, UT USA | Ware D. Branch |

- The randomized controlled trial, titled: *A multicenter International Prospective Randomized Controlled Trial of Hydroxychloroquine in the the Primary Thrombosis Prophylaxis of Persistently Antiphosopholipid Antibody (aPL) Positive but Thrombosis-free Patients without Systemic Autoimmune Disease*, is currently IRB approved at three of the APS ACTION centers and will begin enrollment in 2013.
    - ◊ The purpose of this study is to determine whether hydroxychloroquine is beneficial in reducing the blood clot formation in aPL-positive patients with no history of thrombosis.
- APS ACTION has internationally recruited young scholars who have been contributing to promising and innovative research. So far, the scholars have published and presented two abstracts during this year's American College of Rheumatology (ACR) Annual Scientific Meeting.
    - ◊ Andreoli L, Banzato A, Chighizola CB, Pons-Estel GJ, Ramires de Jesus G, Lockshin MD, and Erkan D on Behalf of APS ACTION. The Estimated Prevalence of Antiphospolipid Antibodies in the General Population with Pregnancy Morbidity.
    - ◊ Chighizola CB, Ramires de Jesus G, Andreoli L, Banzato A, Pons-Estel GJ, Lockshin MD, and Erkan Don Behalf of APS ACTION The Estimated Prevalence of Antiphospholipid Antibodies in General Population Patients with Pregnancy Loss, Stroke, Myocardial Infarction and Deep Vein Thrombosis,

If you want to learn more about or participate in APS-ACTION studies, please feel free to explore our website at www.apsaction.org or contact JoAnn Vega at 212 774-2795 or info@apsaction.org.

# Help for the Holiday Blues

**Submitted by: Todd Ponagai**

The holidays can be a stressful time. The festivities can lead to anxiety related to excessive shopping for friends and family, finding time for social obligations, worrying about holiday debt, and trying to do too much. You can detour from your everyday routine, neglecting proper nutrition and regular exercise. These pressures can lead to the phenomenon known as holiday depression or the holiday blues.

## Will your holiday be blue?

For many suffering from depression, the depression peaks over the holidays. The unrealistic expectations of the season, time and financial pressures, missing loved ones, and reflecting on past events as the year comes to an end can all contribute.

During the holidays, a person can experience depression, loneliness, sadness, isolation, anger, and abnormal sleep. Those who don't experience depression can experience other symptoms such as headaches, tension, fatigue, excessive drinking, and over-eating.

It also is common to feel a holiday letdown after the holidays are over. The hectic holiday period and the feeling of being physically and emotionally drained can leave you with the sense of loss or frustration, and then that can turn into the blues.

The holiday blues can range from mild sadness during the holidays to severe depression, and they are often a normal reaction to life situations.

Holiday blues should not be confused with clinical depression. Clinical depression is a disorder that may need to be relieved with medication, while the holiday blues could require something as simple as a good listener. Clinical depression, however, can be triggered in a number of ways at or just after the holidays.

There is also a tendency to link the holiday blues with seasonal affective disorder (SAD). SAD, however, is a diagnosable disorder that is associated with fewer hours of sunlight during the winter. Although people with the holiday blues also can be afflicted with SAD, the two are not directly related. People with SAD have symptoms of major depression not only throughout the holiday season, but also throughout the autumn and winter seasons.

## Keeping the blues away

The holiday blues may be alleviated with something as simple as getting enough rest. People actually lose sleep during the holidays and end up shortchanging themselves. Consequences of not getting enough sleep might be cloudy thinking, irritability and inability to deal with everyday stress.

Other ways to help ease the blues are to eat a diet rich in fruits and vegetables and to start exercising. Also, make an effort to stay positive.

## Tips to ease the blues

If you are experiencing holiday blues, try to decrease or alleviate them by doing these things:

- Talk honestly to someone.
- Limit alcohol intake.
- Stick within your normal life routine as much as possible.
- Set a realistic budget and then stick to it.
- Establish realistic goals and expectations.
- Do not label the season as a time to cure past problems.
- Don't be afraid to say no. That means don't attend parties when you don't really have time, don't take on obligations that will crowd your time and, don't overextend yourself.
- Find time for yourself.
- Enjoy free holiday activities.
- Try to celebrate the holidays in a different way.

The holiday blues can be quite common, but if you are feeling especially down—for example, your sleep or your appetite is affected—contact your health care provider or visit the National Mental Health Association online at http://www.nmha.org for help and guidance. If you are thinking about suicide, call 911 or your health care provider immediately.

http://healthlibrary.bannerhealth.com/Search/1,2094

# Rituximab Shows Promise for Clinical Problems Tied to Antiphospholipid Antibodies

**Written by: Hospital for Special Surgery**

## May Provide Treatment Option for Those with Harder-to-Treat Memory Problems, Skin Ulcers and Kidney Disease

Rituximab, a drug used to treat cancer and arthritis, may help patients with antiphospholipid antibodies (aPLs) who suffer from aPL-related clinical problems that do not respond to anticoagulation, such as cardiac disease and kidney disease, according to a new study by rheumatology researchers at Hospital for Special Surgery. The study appears online in November, ahead of print, in the journal Arthritis and Rheumatism.

"This is the first study to systematically analyze rituximab in aPL-positive patients. Rituximab may have a role in treating a subgroup of aPL patients," said Doruk Erkan, M.D., senior author of the study, and an associate attending rheumatologist at Hospital for Special Surgery in New York City.

For years, researchers have known that aPLs can increase the production of certain proteins that can cause inflammation and the formation of clots. While some aPL-positive individuals are perfectly healthy, others are classified as having antiphospholipid syndrome (APS) and have venous thrombosis, arterial thrombosis or fetal loss. Patients with so-called "non-criteria APS manifestations" can have low platelet counts (thrombocytopenia), cardiac valve disease, skin ulcers, kidney disease (aPL-nephropathy), and/or memory problems (cognitive dysfunction).

Previously, researchers have shown that B-cells, a type of white blood cell, secrete aPLs and that eliminating B-cells can prevent the development of APS in mice. A number of case reports have suggested that some patients with APS may respond to rituximab. This drug, which can destroy B-cells, is currently used in patients with leukemia and rheumatoid arthritis. "The idea is if you kill the inflammatory B-cells, they can not secrete antiphospholipid antibodies that cause problems," Dr. Erkan explained.

In the current Phase II pilot trial, researchers recruited 19 aPL-positive patients with thrombocytopenia, cardiac valve disease, skin ulcers, aPL-nephropathy, and/or cognitive dysfunction. Patients were given two doses of 1,000 mg rituximab on days one and 15. Investigators measured aPL profiles and clinical outcome measures at baseline, at day 30, and then monthly up to six months.

At 24 weeks, several patients had improved outcomes. Of the five patients with cognitive dysfunction, three had a complete response and one had a partial response. Of the four patients with thrombocytopenia, one had a complete response and another had a partial response. Of the five patients with skin ulcers, three had complete responses and one had a partial response. One of the two patients with aPL-nephropathy had a partial response. None of the three patients with cardiac valve disease had a response. The antiphospholipid antibody profiles of all the patients, however, did not change throughout the study.

"Why is there a response in some patients without decreasing aPL titers?" said Dr. Erkan. "The answer for that is B-cells are very complex; they not only secrete aPL, but they also participate in the immune response by helping other inflammatory cells." In other words, they may be shutting the aPL effect down through other channels.

The authors say that rituximab may offer a potential treatment option for some non-criteria APS manifestations. This is good news, because while anticoagulation therapies can treat some of the complications seen in APS patients, they are not helpful in treating the non-criteria APS manifestations. "The low platelet counts, destruction of red blood cells causing anemia, kidney disease, memory problems, and cardiac heart valve disease do not usually respond to anticoagulation therapy," said Dr. Erkan.

"Our future goal is confirming our results with a randomized controlled trial, and we also need to try to identify which patients will respond to rituximab. We need to find the predictors of response," said Dr. Erkan.

Other authors of the study include Michael Lockshin, M.D., Joann Vega and Glendalee Ramon, all from Hospital for Special Surgery, and Elizabeth Kozora, Ph.D., who is an adjunct scientist at HSS and both professor, Department of Medicine, National Jewish Health, and professor, Department of Psychiatry and Neurology, University of Colorado Denver Medical School.

http://www.hss.edu/newsroom_rituximab-shows-promise-antiphospholipid-antibodies.asp

# APS & the Liver Cyst: A Patient's Story

**Written by: Morris A Nunes**

On October 5, 2006, at age 57, APS suddenly revealed itself to me via a right ocular venous occlusion (right eye vein blood clot). The actual APS diagnosis was made by internist Dr. Howard Goldstein of Bethesda, Maryland through blood tests performed by the laboratory associated with Suburban Hospital in Bethesda, Maryland.

> **"The cause of APS was declared unknown, but was suspected to be essentially hereditary. "**

After interviewing and examining me, Dr. Goldstein suspected that APS might be the cause of the clot. The cause of APS was declared unknown, but was suspected to be essentially hereditary. Because my family history evidenced several male deaths due to sudden fatal heart attacks, this explanation made sense to me.

From there I was referred to hematologists, Dr. Roy Beveridge and Dr. David Dunning, both (at the time) of Fairfax Northern Virginia Hematology & Oncology, PC of Fairfax, Virginia. Coumadin was prescribed. For months, my blood was monitored to be sure the dosage was correctly titrated to maintain my clotting time within a safe range.

Fortunately, after several months, my eyesight returned to normal on its own, though I was regularly monitored by ophthalmologist Dr. Fahdi Nasrullah of Bethesda, Maryland. Dr. Nasrullah had seen me as soon as the clot appeared and I credit his conservative approach to care with sparing my eyesight from undue risk and my full recovery.

Strangely, as I had always been physically active and in good health, (e.g. still regularly playing squash and racquetball) within a short span I also developed several additional medical problems - unusual for me – plantar fasciitis, hypertension, tennis elbow and surprisingly frequent though transient illnesses, mostly of a respiratory nature.

Then, on August 12, 2008, one early evening after work, I was suddenly seized with intense pain in my neck and shoulder, so severe I had to lie down. After a couple of hours and a heavy dose of over-the-counter painkiller, I began to recover, though I did go see Dr. Goldstein two days later as the pain persisted. Over several days the pain had totally subsided.

On September 15, 2008, another event of spontaneous intense pain occurred, again in the early evening. Hanging up from a phone call, I was suddenly doubled over with severe abdominal pain that I classified as an 8.5 on the typical 1-10 Pain Scale. Taken to the emergency room at Suburban Hospital by my wife, a CT Scan revealed a 13 centimeter cyst on my liver. The cyst was promptly aspirated, both to relieve the pain it was causing and to obtain a fluid sample to verify that it was not malignant, which, fortunately was the case. I was told that nearly a standard wine bottle's volume (750 ml.!!) of fluid was ultimately removed from the cyst.

Additionally, I was informed that a benign liver cyst is not uncommon and such cysts are generally ignored, except perhaps to monitor for a potential change to malignancy. For example, the Merck Manual, found at http://www.merck.com, states:

*Isolated cysts are commonly detected incidentally on abdominal ultrasonography or CT. These cysts are usually asymptomatic and have no clinical significance.*

Nevertheless, because of the concern that the cyst would again disable me with pain, I was referred to radiologist Dr. Calvin Neithamer of Fairfax Radiological Consultants, Fairfax, VA, who planned to eliminate the cyst through an interventional procedure.

When I was at Fairfax Inova Hospital and actually on the table prepped for the procedure, Dr. Neithamer cautiously decided to visually check the cyst with ultrasound imaging before proceeding. He determined that the cyst appeared to be shrinking and canceled the procedure, sending me for an MRI to more certainly verify its status. The MRI confirmed his ultrasound reading. Thereafter, I was monitored by MRI over the succeeding two years during which time the cyst was observed to be continually shrinking and resorbing.

My clotting time was also being regularly monitored by the hematologists. In October 22, 2009, Dr. Dunning decided to verify that APS was still present and took me transiently off Coumadin to get a clear reading. I was tested on October 30 and on November 5 the results came in. To our surprise there was no sign of it. The APS was gone. Mot a trace was found. The MRI most immediately preceding the APS test showed the cyst had declined to about 7 cm, or roughly half its original diameter, with the potentially important decline of roughly 71% in volume, assuming the same thickness continued to obtain.

For 6 months, I was monitored without any sign of a reappearance. It seemed also significant that the plantar fasciitis had disappeared, the hyperten-

*(Continued on page 9)*

(Continued from page 8)

sion moderated (but did not wholly disappear), the tennis elbow substantially abated and I seemed to regain my ability to avoid recurrent respiratory illnesses. While I have not had another MRI for many months now, assuming a relatively constant rate of shrinkage (which had been more or less borne out from the MRI's that were periodically performed) I calculate that remnants of the cyst are still present, probably at about 2-4 cm in diameter. My hope and belief is that by the time the cyst has totally disappeared, the hypertension will also fully recede, barring any other independent cause arising.

In February, 2012, Dr. Goldstein again tested, prophylactically, for APS to see if there was any sign of a recurrence of APS. That test was wholly and clearly negative.

We all know that the liver is the factory for blood enzymes. We also know that APS is a condition arising from liver manufacture of lupus anticoagulant factor, which has been generally presumed to arise spontaneously as an auto-immune syndrome. While there is no absolute proof beyond a reasonable doubt for my case, the natural conclusion is that the variety of physical difficulties I was experiencing, most notably and dangerously APS, was coincident with and a result of the "benign" cyst that bedeviled my liver. Further, the interruption and recession of that cyst was coincident with the remission of APS and other concurrent maladies.

There was no certainty as to the genesis of the cyst in terms of either cause or onset, though it certainly would appear to precede the APS ocular manifestation in October, 2007. One theory was that I had experienced a trauma to the liver that generated the cyst. The most likely trauma had occurred on the squash court when I had accidentally managed to literally impale myself on the handle of my squash racquet by momentarily running into it when it was perpendicular to the court wall as I attempted to hit the ball as it ricocheted therefrom. Luckily, the point of body strike was at stomach level below my rib cage and above my groin. The theory went that the impact caused my liver to rebound against my rib cage and that bruise morphed into the cyst.

Whatever the cause, it seemed that aspiration had catalyzed the cyst to stop its growth and initiate its shrinkage. It is noteworthy that such aspiration is generally unusual and even considered by some to be contra-indicated as a proper therapy. Regardless, it seemed to be a godsend for me.

The really significant indication is, of course, that the etiology and cure of APS seems wholly related to the corresponding advent and decline of the liver cyst. Of course, this is a purely anecdotal manifestation and remission of APS, but it suggests that those patients who present with APS might be screened for liver cysts or perhaps other liver abnormalities, and if found that those be treated.

As a corollary, it also appears to suggest that the traditional view of benign liver cysts as best left alone other than to monitor to be sure they do not turn malignant may not be the wisest medical approach, especially if the patient is manifesting a material change in health, of which APS may be a significant marker, though not necessarily one that would be guaranteed to be present.

# The Consultation

**Written by: Rowena Silver**

Sjögren, grazing in dried meadows,
deserts innocent of rain,
seasons parched and grasses sterile,
gazed into her reddened eyes,
“Mine he said, “This one is mine.”

Meniere presented, pirouetting,
grabbing passing tiles and lives,
flutes assailing from white distance,
“No,” he said. “This one is mine.”

Schatzki tried to force down rations
at the squamocolumn stage,
undulating dry tight juncture
he divined: “This one is mine.”

Raynaud laid claim,
as she lay, winded,
cold blue hands now blanching white,
ANA positive and glowing
Drowsiness without a dream.

Hashimoto saw the pattern,
from the bleachers, at the side,
saw the order of progression,
saw the chorus leaning forward,
felt the weary joints and muscles
saw the reddened cheeks and flushes
saw the wolf outside the window,
Lupus, lurking at the door.

*Rowena Silver is a poet and play-write from Winnipeg, Canada, now living in Riverside, CA. She is an editor of “Epicenter Literary Magazine.” Rowena has been diagnosed with Lupus and APS.*

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