ANTIPHOSPHO...WHAT?

APS Foundation of America, Inc. Newsletter
Volume 19 Fall/Winter 2010

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

A Joyous Holiday Season!

The Global State of Autoimmunity Today

Written by: Jean Ann Weller


Kellie Martin, spokesperson for AARDA and Virginia Ladd, President and Executive Director for AARDA

On September 24th, I attended "The Global State of Autoimmunity Today: Autoimmune Disease Patient Advocacy, Research Advances and Obstacles, Environmental Impact on Immunity and International Testimony at the Church Center for the United Nations. Tina needed a representative from APSFA but omitted one very small item - the UN was on lockdown due the General Assembly being held across the street and the City was basically in lockdown mode. There were cops and Secret Service EVERYWHERE. Not that we didn't enjoy all the hoopla as my husband and I are both retired from the NYPD so it was hard for us to even get around.

It was sort of overwhelming for me. I was sitting in a room with people that knew all about what I suffer from, how I got it and where it can take me. It was almost a feeling of understanding. Upon arrival, I introduced myself to a few, proudly displaying my APSFA pin. I distributed some literature and then sat down to listen to these "heroes" that play such huge roles now and in the future.

Approximately 50 million people have autoimmune, 75% of them being women. I found it pretty amazing to even hear these professionals tell how misunderstood autoimmune illnesses are and how many years it takes the average person with an autoimmune illness to get a proper diagnosis, some average seven years and some never get a proper diagnosis. It is believed that, in the future, a person will be able to be tested for an autoimmune disease and treated PRIOR to the disease taking over your body. This person would be tested for their "AQ" (Autoimmune Quotient) and the "environmental factors" that would trigger the autoimmune response removed.

Noel Rose, MD, PhD, is the Director for the Center for Autoimmune Research at Johns Hopkins. Mr. Rose spoke in non-medical terms and was very easy to understand. He discussed the "who, why, when and what we can do". There is absolutely, positively a genetic predisposition and inherited tendency for autoimmune disease. They believe that autoimmune disease can be triggered, in women, by landmark hormonal changes, for example, the birth of a baby, puberty or menopause. They know that genetics plays such a huge role by studying identical twins, whose DNA is exactly the

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Click Below to Follow APSFA

Newsletter Articles Needed!

We are in need of APS related articles such as book reviews, poems, recipes, interest articles, quotes, etc. for our newsletters.

We also need patient stories to feature in our newsletters, especially about men or children who have APS. Every APS patient has a story to tell and yours could be shared with the entire APS community.

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 just about gone and some snowflakes are in the air so many of us are getting ready for the Holiday Season. Once again the year has flown by. It seems each year it happens faster and faster.

At the Holiday Season, our thoughts turn gratefully to those who have made our progress possible. The APS Foundation of America, Inc is asking you to please consider us for your end of the year contributions and / or holiday donations. We are the first and leading foundation in the United States dealing specifically with APS, and one of only three in the world. If you or your company is looking for a charity to donate to, please consider the APS Foundation of America, Inc. We are a non-profit public charity; therefore all donations are tax deductible. If your family has ever been touched by heart attack, stroke, pulmonary embolism, or pregnancy/infant loss, our foundation welcomes you to join us as well. Without your help, the APSFA, it support forum and awareness could not happen.

The APS Foundation of America is actively working with our medical advisors and their respective facilities to get the education out about APS. We have been contacting various newspapers and media sources to get the word out about APS and the foundation. We have also been busy attending many patient and professional conferences to get the word out about APS & the APSFA. We have even had the opportunity to meet actress, Kellie Martin. Some of you may not know that Kellie had a sister, Heather, who died from Lupus at the age of 19.

We have many holiday items in our Café Press Store at http://www.cafepress.com/apsfoundation including our annual snowflake ornament & holiday cards. Once again, Heidi has done a wonderful job creating these designs. This is a great way to send out holiday cheer and support the APSFA as the same time. Also, please check our Giving Tree. This is our largest fundraiser of the year. This tree holds a special meaning to the APS Foundation of America, Inc and the community it serves. We hope you will help decorate our Giving Tree. You can find our Giving Tree here: http://www.apsfa.org/givingtree.htm.

We have also been awarded "The Hope Reward" Our website now joins a select group of health websites that adheres to the highest standards of health information quality, ethical behavior, and respect for consumer privacy.

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 throughout the coming year!

Sincerely,
Tina Pohlman
President & Co-Founder

APSFA Board of Directors

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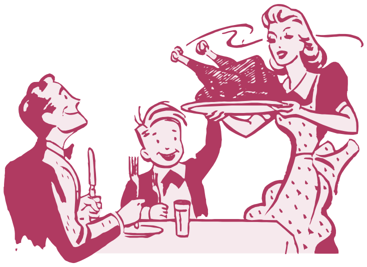
Stress, Depression and the Holidays: 10 Tips for Coping

Written by: Mayo Clinic Staff   Submitted by: Tina Pohlman



Stress and depression can ruin your holidays and hurt your health. Being realistic, planning ahead and seeking support can help ward off stress and depression.

The holiday season, which begins for most Americans with Thanksgiving and continues through New Year's Day, often brings unwelcome guests — stress and depression. And it's no wonder. In an effort to pull off a perfect holiday, you might find yourself facing a dizzying array of demands — parties, shopping, baking, cleaning and entertaining, to name a few. So much for peace and joy, right?

Actually, with some practical tips, you can minimize the stress and depression that often accompany the holidays. You may even end up enjoying the holidays more than you thought you would.

Recognize holiday triggers

Learn to recognize common holiday triggers, so you can disarm them before they lead to a meltdown:

- Relationships. Relationships can cause turmoil, conflict or stress at any time, but tensions are often heightened during the holidays. Family misunderstandings and conflicts can intensify — especially if you're thrust together for several days. On the other hand, facing the holidays without a loved one can be tough and leave you feeling lonely and sad.
- Finances. With the added expenses of gifts, travel, food and entertainment, the holidays can put a strain on your budget — and your peace of mind. Not to mention that overspending now can mean financial worries for months to come.
- Physical demands. Even die-hard holiday enthusiasts may find that the extra shopping and socializing can leave them wiped out. Being exhausted increases your stress, creating a vicious cycle. Exercise and sleep — good antidotes for stress and fatigue — may take a back seat to chores and errands. To top it off, burning the wick at both ends makes you more susceptible to colds and other unwelcome guests.

Tips to prevent holiday stress and depression

When stress is at its peak, it's hard to stop and regroup. Try to prevent stress and depression in the first place, especially if the holidays have taken an emotional toll on you in the past.

1. Acknowledge your feelings. If someone close to you has recently died or you can't be with loved ones, realize that it's normal to feel sadness and grief. It's OK to take time to cry or express your feelings. You can't force yourself to be happy just because it's the holiday season.
2. Reach out. If you feel lonely or isolated, seek out community, religious or other social events. They can offer support and companionship. Volunteering your time to help others also is a good way to lift your spirits and broaden your friendships.
3. Be realistic. The holidays don't have to be perfect or just like last year. As families change and grow, traditions and rituals often change as well. Choose a few to hold on to, and be open to creating new ones. For example, if your adult children can't come to your house, find new ways to celebrate together, such as sharing pictures, emails or videotapes.
4. Set aside differences. Try to accept family members and friends as they are, even if they don't live up to all your expectations. Set aside grievances until a more appropriate time for discussion. And be understanding if others get upset or distressed when something goes awry. Chances are they're feeling the effects of holiday stress and depression too.
5. Stick to a budget. Before you go gift and food shopping, decide how much money you can afford to spend. Then stick to your budget. Don't try to buy happiness with an avalanche of gifts. Try these alternatives: Donate to a charity in someone's name, give homemade gifts or start a family gift exchange.
6. Plan ahead. Set aside specific days for shopping, baking, visiting friends and other activities. Plan your menus and then make your shopping list. That'll help prevent last-minute scrambling to buy forgotten ingredients. And make sure to line up help for party prep and cleanup.
7. Learn to say no. Saying yes when you should say no can leave you feeling resentful and overwhelmed. Friends and colleagues will understand if you can't participate in every project or activity. If it's not possible to say no when your boss asks you to work overtime, try to remove something else from your agenda to make up for the lost time.
8. Don't abandon healthy habits. Don't let the holidays become a free-for-all. Overindulgence only adds to your stress and guilt. Have a healthy snack before holiday parties so that you don't go overboard on sweets, cheese or drinks. Continue to get plenty of sleep and physical activity.
9. Take a breather. Make some time for yourself. Spending just 15 minutes alone, without distractions, may refresh you enough to handle everything you need to do. Take a walk at night and stargaze. Listen to soothing music. Find something that reduces stress by clearing your mind, slowing your breathing and restoring inner calm.
10. Seek professional help if you need it. Despite your best efforts, you may find yourself feeling persistently sad or anxious, plagued by physical complaints, unable to sleep, irritable and hopeless, and unable to face routine chores. If these feelings last for a while, talk to your doctor or a mental health professional.

Take control of the holidays

Don't let the holidays become something you dread. Instead, take steps to prevent the stress and depression that can descend during the holidays. With a little planning and some positive thinking, you may find that you enjoy the holidays this year more than you thought you could.

Source:

http://www.mayoclinic.com/health/stress/MH00030

Different Ways To Donate To The APSFA This Holiday Season

Written by: Heidi Ponagai

The 2010 Holiday season is sneaking up on us faster than we think! It is the perfect time to start thinking about where your holiday charity donations are going this year. This page is dedicated to the many different ways you can donate to the APS Foundation of America, Inc. during 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 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 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.

◆ On our shopping page, we have links to amazon as well as GoodSearch shopping. When you use these sites to do your online shopping, the APSFA gets a small percentage of the sales!

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

www.apsfa.org/donate.htm

Please be sure to have all donations for 2010 post dated by 12/31/10.

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

APSFA Online Giving Tree

The APSFA "Giving Tree" is an annual holiday tradition! 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 past years, 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 will be printed underneath the tree.

Ornaments can also be in memory or in honor of someone and this year they will have a little different look to them so they stand out from the rest of the decorations.

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

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The APSFA CafePress Online Store

We have a wide selection of APSFA, APS, Hughes, Lupus, infant loss and thrombosis gear located in our CafePress online store.

With every item purchased, the APSFA receives a small donation. We have made over $1000 so far in 2010 just with CafePress sales!! Thank you to everyone who's purchased our items!

For those people who are not familiar with our store, we have items like t-shirts, sweatshirts, teddy bears, aprons, buttons, magnets, 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.

This year is the 5th year for our annual exclusive APSFA Keepsake ornament. We 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.

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

Shari's APS Story

Written by: Shari Akers

Hello, my name is Shari Akers. I have had a tough life and nobody ever knew why until 2005.

I had four miscarriages. I was diagnosed with a brain tumor in 1986. The tumor turned out to be a group of ruptured blood vessels in my brain that had "burst and calcified" sometime during my youth. The calcification was causing the "signals" in my brain to mis-fire, so the tumor was removed and I went from 4-5 seizures a day to none.

> **"I said, (through the same gasps of air), "I am NOT dying! My heart is fine. My brain is fine. I will be fine! Just get rid of the clots!"**

I had one child, followed by a complete hysterectomy due to massive blood clots and painful, "hemorrhagic cysts" that grew larger than a grapefruit on my ovaries. I was only 22 when my daughter was born and I was only 27 when I became unable to have any more children. I adopted 4 children from my husband's first marriage.

In 2005, I was bit by a spider, a "Brown Recluse" I was told. I was off my feet for five or six days. On the seventh day, when stepping out of the shower, I felt terrible pain in my chest. It did not feel like anything related to my heart, more like something forcing its way into my chest, making it feel like my breasts were being turned inside out in the process. I sat on the edge of my bed and waited. Nothing happened except pain - a lot of pain. I started to cough, which forced a deep breath, the pain would subside for a moment, but then pain again. I went to the ER at our nearby hospital. I relayed my story to the ER doctor through gasps of air. He told me I had bronchitis and sent me home. The next day was much worse. I went back to the ER and the doctor told me, "You may be getting pneumonia. If it gets worse, come back. Otherwise, see your doctor on Monday." This was Thursday morning. Friday morning I tried to get out of bed, but could not breathe. I coughed and coughed and coughed. I called my daughter at work. The loudest I could speak with the amount of air I could get in my lungs was a soft whisper. I could only say two or three words at a time before I would cough again, inhaling a little more air with the after the cough. I said, "I can't breathe. Take me to the other hospital."

The "other hospital" is a larger hospital about three times as far from our home as the first hospital. I was taken back to the examination area of the ER where my daughter tried to explain the sequence of events to the ER doctor. He looked at me and said, "Yeah, if I coughed like that, my chest would hurt too!" I grabbed the doctor by the tie and whispered, "Listen to me. It hurts, I can't breathe. I cough, I get air, the pain goes away for a few seconds, then it starts over. The cough helps the pain by giving me oxygen." The ER doctor said, "Oh, I see what you mean. Well, what do you think is wrong with you?" I whispered, "P.E." The doctor's eyes got huge, neither ER doctor thought of this! I told them I was lying in bed for a few days with sudden, non-cardiac chest pain with shortness of breath and coughing. What else could it be?

They did some tests and found I had a "massive DVT (Deep Vein Thrombosis) in my left leg that went from above my knee, around my knee and down to my calf. I had a VQ nuclear scan for PEs, (Pulmonary Embolism), blood clots in my lungs. I was admitted and wheeled upstairs to a private room.

I was coming out of the bathroom in my room when I heard two nurses calling my name, "Mrs. Akers, Mrs. Akers, where are you? Oh, there you are, please get back in bed right now! We are moving you to a different room." I said, "Shouldn't I get in the wheelchair?" They looked at the floor and shook their heads, "No, we are moving you in your bed. You are not to get out of your bed AT ALL, for ANY REASON."

I said, "I have a PE, don't I?" They nodded their heads, "Yes, the doctor is on his way up."

I was in my new room, started on five liters of oxygen and IV pain medication. The pulmonologist came up to my room. He said, "Well, you are supposed to be dead, but since you didn't die, I guess I'm supposed to keep you alive." I said, "I know the nurses told me I have a PE." The doctor scoffed, "A PE?!? You have MULTIPLE, BILATERAL PEs! I cannot even see your right lung! I am not kidding, I don't know why you are alive! We find these things in autopsies!"

Then I started to get scared. That was July 5, 2005. I was discharged November 29, 2005. You see, every doctor and specialist who saw me was convinced it was just a matter of time before I died. I was given "....medication to keep me comfortable," every 2-3 hours, round the clock. "We have to keep you calm and quiet. Keep you relaxed, your blood pressure low. We want you to be comfortable until, well you know." I said, (through the same gasps of air), "I am NOT dying! My heart is fine. My brain is fine. I will be fine! Just get rid of the clots!" Finally, a hematologist/oncologist specialist came in. He drew about 1 cup of blood and ran more tests than I can remember.

The result: "You have Antiphospholipid Antibody Syndrome." I said, "I have WHAT?!?" He said, "It is like Lupus - sort of. Do not worry about it now. It explains everything. Your miscarriages, the bursted blood vessels in your brain, the problems you had leading to your hyster-

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APS Updates from the American College of Rheumatology (ACR) Annual Meeting - Nov 6-11, 2010: Some Peachy Results from Georgia

Written by: Gale A. McCarty MD, FACP, FACR
Center for Rheumatology/Inflammation/Lupus and APS, and Rheum.Ed Consulting, Ellsworth ME 04605

To the countless patients worldwide with antiphospholipid antibody syndrome (APS) by itself, and those with APS and systemic lupus erythematosus (SLE) or other systemic rheumatic diseases, we, the physicians from multiple specialties, clinical and basic researchers, and your other caregivers salute YOU for your “patience as patients” in the fight to conquer APS. Your willingness to contribute your medical data, blood, cells, and time to help identify new clinical features, improve diagnostic tests, and to pursue our mutual goals of better, more specific treatments is what makes our APS world go round. This week, the world was treated to some “peachy” results from Atlanta, the home town of the ACR.

Multicenter and multinational collaborations continue to be productive, as hundreds of heads are better than one! The Clinical Research Task Force formed at the XIIIth International Symposium on APS in Galveston TX April 2010 cited an urgent need for the formulation of good research questions to achieve “Finer Criteria” (eg. studies that are **f**easible, **i**nteresting, **n**ovel, **e**thical, and **r**elevant)[1]. This is best achieved by standardized tests for aPLs, prospective (“looking ahead”) studies, preferably population based. A very important blood protein, β_2-glycoprotein I, has been found by Dr. Ioannou et al to have different forms in APS patients, not just due to protein sequences, but to modifications in the circulation after it is made, called oxidation. These forms are more likely to bind β_2-glycoprotein I and result in a blood clot than others.[2] New data about β_2-glycoprotein I -aPL binding to target cells involving the apolipoprotein E receptor 2 from Dr. Romay Penebad et al show this apo-ER2 receptor is responsible for helping to cause some of the clots and blood vessel damage in a model using both mouse and human antibodies.[3] Dr. Lambrianides et al looked to see if drugs such as statins and hydroxychloroquine (which have been shown to have some roles in decreasing APS pathology in animal models but not in large Randomized Control Trials in humans) could affect protein expression in monocytes from APS patient who had blood clots, and found that in the case of statins, 24 proteins were affected, and for HCQ, 5 proteins were.[4] These novel findings may help investigators guide the development of new therapies beyond currently used anticoagulants to take advantage of ways to decrease “bad “ forms or amounts of proteins expressed on or in cells involved in the immune system or in coagulation.

Since I started the ACR APS Study Group in 1990, Dr. Pierangeli has chaired it many times, and again composed a wonderful program that was attended by over 200 people. Please note: Study Groups do not publish Abstracts, but readers are directed to search these Presenters’ other work under the ACR Annual Meeting Abstracts tab (www.rheumatology.org). Dr. A. Rahman emphasized that while this year there are no randomized controlled trials of new therapies, there are 2 new anticoagulant medications with different ways of acting to undo blood clots. He and his colleagues are also exploring different ways lab tests and clinical features combined might help to better predict what patient will develop what type of clot; none of these are perfected yet. Dr. S Krilis enhanced our knowledge about the binding domains and specificities of β_2-glycoprotein I , and new tests to further define autoantibody binding structure-function correlates. Dr. Thomas Ortel reviewed the current criteria for the performance of the coagulation-system based tests for aPLs, with updated guidance from the International Society for Thrombosis and Haemostasis which had not been updated for a decade. Anyone ordering aPL tests has to know how to be sure the lab they use is doing both the initial screening tests and the second-level confirmatory tests correctly. Dr. Jane Salmon updated the PROMISSE Study (Predictors of Pregnancy Outcomes: Biomarkers in APS and SLE) where pregnant patients with various combinations of APS with and without SLE, and controls who only have aCL tests but no clots or lupus, were carefully classified by having all testing for the immunologic -based aPL test CONFIRMED by a central core lab. She made the point that approximately 40% of the tests done by other labs at the time the patients were referred to the study were incorrect. The presence of a positive coagulation-based test was very predictive of pregnancy problems, small babies, and toxemia or preeclampsia. Dr. E Nigel Harris summarized the “wet lab workshops” conducted at the XIIIth ISAPA to compare the various ELISA-based immunologic tests for aPL with actual performance data about usual tests, emphasizing the availability of calibrators and performance standards. It is to Drs Harris and Pierangeli that the world owes thanks because since the early 1980s they made available to eve-

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same. If one identical twin has autoimmune, the second twin is TEN TIMES more likely to develop autoimmune disease. He spoke about how the only thing we can control about autoimmune diseases is "environmental" that can be altered where genetics cannot.

Most of the doctors spoke of the geographical portion of autoimmune illnesses. By mapping and identifying autoimmune illnesses, we are able to tell where certain diseases are most prevalent, such as diabetes and rheumatoid arthritis. It is obvious that the further away we live from the equator, the more likely we are to get autoimmune illness. It was a numbing subject and many of us sat there shaking our heads, seeing how some countries are just riddled with one particular autoimmune disease. Just shocking!

I had an opportunity during a break to sit and talk with Kellie Martin, the AARDA spokesperson and actress. She described to me how autoimmune illness has effected her family and I told her how it has effected mine; that I knew little about the stomach aches I got as a teenager, the unexplained fevers, the hospitalizations where I was diagnosed with a "virus", only to be re-hospitalized. How I finally discovered that I had APS after being diagnosed with numerous DVT's and bilateral pulmonary embolism. Dr. Samuel, my hematologist, sat next to me on the hospital bed telling me how lucky I was to be here. That my lungs were "riddled" by pulmonary emboli and there was a definitive cause to my DVT's and PE's.

Kellie Martin and Jean Ann

Originally blaming lupus, it wasn't until February that a rheumatologist diagnosed me with APS. I actually left the office happy that I had APS and not lupus. Boy was I confused. Then I came home and went online and cried. My daughter, a child of 15, has been stricken with Raynaud's Syndrome at the age of 13 and my 12 year old daughter gets chronic "FUO's" (fevers of unknown origin). My Dad had diabetes, my brother has Rheumatoid Arthritis and my Mom had thyroid cancer. My entire family has been stricken and affected by autoimmune illnesses.

Overall, this was a very informative meeting and well worth the drive and headache to get to the United Nations and was proud to represent the APSFA at this session.

10th Annual Living Well with Lupus Symposium

Written by: Jessica Selig

Over 130 participants joined the Lupus Foundation of America, Philadelphia Tri-State Chapter for the Living Well with Lupus Annual Symposium this past Saturday, October 2, 2010.

Joan T. Merrill, MD

The students in the Youth in the Loop for Life program at Springfield Township High School graciously acted as the hosts and hostesses for our event which took place in their High School.

Joan T. Merrill, M.D., the Medical Director of the national Lupus Foundation of America presented the keynote presentation: "Lupus in the Lab: Lupus Expert Weighs in on the Future of Lupus Research." Dr. Merrill's passion for lupus research and high energy shone brightly throughout the presentation.

Other highlights of the day included workshops from Lawrence Brent, M.D. and Joan von Feldt, M.D. Throughout the symposium, participants discovered various exercise options for better health and explored the relationship between mind, body, and spirit and how it relates to living your best life. A special workshop was offered for the family, friends and loved ones of our participants with lupus and offered suggestions on how to take good care of oneself, even while caring for a loved one.

The symposium adjourned after closing remarks from Annette Myarick, CEO of the Lupus Foundation of America, Philadelphia Tri-State Chapter and Cheri Perron, Chair of the Patient and Community Services Committee. Annette and Cheri offered suggestions for the benefits of raising awareness of lupus, and the hope that the awareness will bring to all people affected by lupus.

I was able to educate people about APS and the APS Foundation of America, Inc. The symposium was very educational and I look forward to attending it next year and representing the APSFA.

The APS Foundation of America is issued GuideStar Exchange Seal: Partner in Trust

Written by: Tina Pohlman

GuideStar has issues the GuideStar Seal: Partner in Trust to the APS Foundation of America, Inc. This is a very important seal to the APS Foundation of America, Inc. It ensures transparency of our 501(c)3 public charity.

Here is a brief overview of what the seal means. The GuideStar Exchange is an initiative designed to connect nonprofits with current and potential supporters. With millions of people coming to GuideStar to learn more about nonprofit organizations, the GuideStar Exchange allows nonprofits to share a wealth of up-to-date information with GuideStar's vast on-line audience of grantmakers and individual donors.

Exchange members are nonprofits that have updated their nonprofit reports to the fullest—sharing information, documentation, photos, and video with GuideStar's visitors.

The APSFA hopes this seal further gains your trust in our organization.

For more information please see GuideStar's website:

http://www.guidestar.org

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ectomy. All of these things can be directly linked to Primary APS."

They drained 2.5 liters of fluid from my right pleural space and my right lung reappeared. They drained another .50 liter from my left lung. My breathing got better. I was on IV Heparin. I had an IVC, (Inferior Vena Cava), filter placed by going through my jugular vein, then through my heart. I was started on Warfarin which I will take until the day I die.

I was essentially kept in an awake, but drugged so I could not move state for four months. Everything a person does in their day-to-day life, I did in my hospital bed. My oxygen saturation was 80 on 5 liters of oxygen when I arrived. It was about 93 toward the end of my hospitalization. The last four weeks or so of my hospitalization was for physical therapy to teach me how to walk and stand from a sitting position again. I lost all muscle tone from being in bed for so long. As soon as I could walk, I was discharged.

I bred, raised, trained and rode horses until that terrible day in July in 2005. I still have two horses. However, my doctors tell me that, since I am on warfarin, I should not, absolutely should not, take any chances riding my horses anymore. I told them, "I know how to fall off a horse. I've been kicked before, I've been lucky, nothing has ever happened to me." They told me, "It is not the injury that you can see and feel that we worry about. You can fall off your horse, get thrown or kicked and feel fine. But, because you are on warfarin, you could be slowly bleeding to death on the inside."

That was a very sad day for me. I have ridden horses since I was four years old. Now, I just walk around the field with them. However, I always have the image of bleeding to death in my mind when they start running and playing in the paddock or field while I am out with them.

I do not want to die from APS. I do not want to die from PEs or DVTs. I do not want to die because I got hurt enjoying something that was such a big part of my life. I don't know what to do. My horses have a very easy life now - living as gorgeous "pasture ornaments."

I pray for a cure everyday. I am tired of pretending I am not tired too. Why does such a debilitating illness have to be so invisible to everyone else? People that don't understand it, don't believe me or "get it" when I say, "My joints are killing me. I can't walk today. I'm really tired." It isn't like that everyday, but when those flare-ups happen, they come on with a vengeance. I work at a children's hospital in the business office. Nobody there understands, or even tries to understand, when I am having a painful, miserable, day.

I rejoice the good days and know the bad days will pass.

(Continued from page 6)

ryone the ability to a) have one's lab certified by them in the performance of the ELISA aPL tests using their standards onsite at their labs or at meetings, and b) the use of their calibrators to standardize "home grown" or commercial assays. Their generosity has helped to foster collaborative large studies from which we have already reaped benefits, with more to come!

Sources:

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My Husband, Nathan's APS Story

Written by: Clare Polencheck

On one of the first days of June in 2007, my husband Nathan pulled a groin muscle rounding third base during church softball. It was obviously tender, but a few days later his thigh started to swell pretty heavily. His leg began to turn a darker red. His walking became labored and we were beginning to get worried. He was RICE-ing, but it got worse and worse. Of course, he looked up his symptoms on the internet and happened to find "blood clot" among the possibilities. We went to Urgent Care to get it checked out, and when Nathan expressed to the doctor that he was concerned he had a blood clot, the doctor laughed and said, "You're too young to worry about that." It was just a muscle strain, we were told.

Nathan sportin' a stylish compression stocking. Try shopping for pants with two different sized thighs!

Three days later I woke up in the early morning to Nathan whimpering (this kid doesn't whimper.) and off to the ER I dragged him – literally! He couldn't walk, let alone find a shoe that fit his massively swollen foot, and could barely manage to put a pair of gym shorts on over his huge purple leg. We saw a different doctor who, upon seeing Nathan, told him to sit very still and not move. Huh? A short time later, Nathan's leg was ultra sounded, and he was found to have the largest single blood clot that our hometown hospital has ever seen. The ER staff freaked out and they worked quickly to start pumping him full of whatever it was to break up the clot. He was put up in a really nice room and had about a week long stay in which he was closely monitored and administered blood thinners and drugs to break up the clot as well as major doses of pain medication.

At the time, I didn't really know what a blood clot was, or that it was a big deal. Nathan had deep vein thrombosis, or DVT in his thigh and the danger of this I later learned is the clot breaking and moving to the lungs, causing pulmonary embolism, which is why he was instructed to be very still. The size of Nathan's clot was so significant that death was a pretty high danger. I also learned later that the room Nathan was put in at the hospital was the hospice room. This enlightened me further to the severity of his condition at the time.

So out of the drama we learned that Nathan has APS. It isn't catching, but studies are underway to see if it is genetic. For a year after his DVT, he had to wear these hot compression stockings, and he has permanent swelling damage in his leg. It is impossible to find pants to fit unsymmetrical sized legs! He also has to be on blood thinners for the rest of his life, get regular "INR" checkups (INR- some number that relates to how fast the blood clots), and watch his vitamin K levels, which affect the blood thickness. He has to try to eat the same amount of green veggies every day to keep it balanced. Good thing I'm a food Nazi. The recovery from his DVT was extensive, and continues now. The vein that was damaged is pretty much "dead" and his body has had to create new pathways for the blood to move through his leg. Cardiovascular exercise can be a big challenge due to the heart working over the top to push blood through the damage, but he has worked hard over the last 3 years to recover his "wind."

Looking back on his history, Nathan noted an incredible ability to heal quickly which he now attributes to his "thick blood" and fast clotting. Cuts and bruises had always disappeared pretty fast, and his recovery time from gym workouts was described as "un-human." When muscle is worked hard, as in strength training, it tears. Healing of the muscle is what builds it.

Muscle hugeness due to APS? I'm not a scientist, but could this definitely be a factor? I think so - along with my amazing cooking skills of course.

From the list of issues above, he also suffered from *migraines* in which he *lost vision and sensation* on one side of his body, and he had terrible rhythm. (This may be a stretch, but I'm attributing this to *neurological symptoms such as abnormal movements*.) Now he hasn't had a migraine since his DVT episode, and he's an avid drummer! Which incidentally has become a wonderful form of non-impact exercise for his leg.

He'll always have to be careful and watchful but with his case, already having gone through the near death DVT, knowing about the APS eases much of the battle at this point!

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