June is APS Awareness Month
Written by: Tina Pohlman & Dana Stuart

With June being APS Awareness Month & June 9th being the Third Annual World APS Awareness Day, we are asking you to get involved with spreading awareness by sharing our newsletters, graphics, public service announcements, and press releases on the social networking sites you belong to. We know many of you are on sites such as Facebook and Twitter. If everyone shares one link, posts one bulletin, and/or tweets about APS Awareness and asks their followers to retweet it, we could potentially reach millions of people!!

Links for our social networking pages are available on the front page of our website as well as on our support forum and newsletter. We already have blinkies, badges and flair that can be added to blogs or used as avatars during the months of June.

We are asking you to talk about APS in your various support groups and even mention it in your non-APS support groups. Or, if you blog, write a blog about it and ask people to link to your blog post. The goal is to get APS to be a familiar name in the medical & autoimmune communities.

Where can you find this information? It is all over the place! But here are good starting places for you to begin educating those around you and in your network: http://www.apsfa.org/media.htm and here http://www.youtube.com/user/APSFA.

You will also find photo albums that can be shared on Facebook. We also have a tweet sheet located here: http://is.gd/RVvyHJ.

These work great not only for Twitter but for Facebook as well.

Don’t be afraid to contact your local media and ask them to do a story about your and your battle with APS. Explain why it is important for them to cover APS this month.

We realize that money is tight for many people so we haven’t been actively soliciting for donation but we do ask you to check out our new designs available on Café Press at http://www.cafepress.com/apsfoundation. Not only will you have a cool awareness item to wear but you know that 100% of the proceeds go to the APSFA to help us provide information packets to those who request them free of charge.

If you’d like to get involved and need help finding information, please contact us through the APSFA website. You may only be one person, but your one post could catch the eye of a new patient and bring them to our site so they can get the information they need and that is what awareness is all about!

So, while we continue to press on for a cure, please help us spread awareness on this horrible disease. It is time to cure this Silent but Deadly disease!
Letter from the President

Wow, May in Wisconsin and I must say it has been pretty hot for the most part. Local media says Winter was over here basically in January. I am not going to argue.

We are in serious 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!

June is APS Awareness Month and with that this makes it our 7th year in official operation. Where has the time gone? Each year there is more and more to do. Please watch the APSFA website and Facebook Fan page for updates and things happening during APS Awareness Month.

The APSFA will also be donating $3,000 towards the purchase of a medical grade freezer for APSACTION to keep their specimens frozen properly. We hope at the end of the year to donate more.

Café Press is growing again. We are adding more and more products everyday. Check out our store at http://is.gd/mrEZlu. As always, 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 newsletter at http://is.gd/AV0Uk9. We are planning on sending special articles out that will only be available to those that are on our email list. Ask your friends, family, care givers (including your doctors) to join our mailing list. There is always something in our newsletter that they can learn.

I must apologize that I am still behind on some APSFA items. Between my health, my numerous doctor appointments, lab draws, chronic pain & other responsibilities in my personal life I have just been swamped. So, please bear with me. After June, I will be changing my available phone hours. I have realized my health has to come first.

That is about all the news I have to report. Once again, I hope this newsletter finds you in the best of health and with a perfect INR level.

Sincerely,

Tina Pohlman

President & Founder
My name's Heather Andrews, 31 years old, diagnosed with primary APS and a host of blood mutations in 2005-2006, following the death of my son Gabriel due to blood clots in his lungs. I'm a Clark County licensed electrician, a Nevada state licensed solar power installer, and first-level NABCEP certified in photovoltaics as well.

I included these photos because so many doctors seem amazed that I am not only able to work, but to work outside as well, and go to school (and teach classes!) on top of it all. Yes, I'm exhausted a lot of the time. There are days that I'm in pain, or dizzy, or overly emotional due to the APS. I take more sick days than most in my trade, and it's noticed by my supervisors. I can either keep up with what I'm doing or just give up, and after all this I refuse to let APS take over.

After several miscarriages, I found I was well into my first trimester with Gabriel the day after I returned from a 3-week trip to Europe in June 2005. I was extremely nervous, but I was diligent to keep all my appointments with my OB, my nutritionist, my primary care physician. I did everything by the book, and even my primary care physician joked with me once that pregnant women are allowed to be laid back once in awhile. I immediately went to light duty with my company, an electrical contractor, so I wouldn't be on a construction site. I was given a temporary desk job, and I found myself incredibly exhausted at all times and even fell asleep throughout the day. My doctor said it was normal, and I believed her.

My fiancé (now husband) Nathan and I were engaged before I became pregnant, and we decided to move the wedding date up a few months to make sure the baby was born in wedlock. It took some extra planning and we sacrificed a bit to do so, but we felt it was the right thing to do. I was careful not to buy anything for the baby, because I was so nervous about the pregnancy, but I'd get excited each time I passed a Toys R Us.

Six days before our wedding date, I began having heavy vaginal bleeding. I went to the ER immediately and was admitted. When they tried taking a blood sample, they found my blood to be so thick they had to use special needles and a machine to get it out. It looked like gelatin. Two days later, I spoke with a perinatologist who had reviewed my case and told me that the outlook wasn't good at all. Since I wasn't in active labor, they chose to discharge me.

Nathan and I were married as planned, and although a happy occasion, it was overshadowed by the pain and anxiety of possibly losing our son. I'd asked the doctors if we should call off the wedding, and they all said that as long as I didn't go crazy dancing and drinking, I'd be fine. No honeymoon intimacy either which was a disappointment to both of us, but we knew the necessity of it.

Five days after our wedding, I began bleeding again. I was re-admitted, and gave birth almost 24 hours later at almost 6 months pregnant. Gabriel Taeyang (Korean for "most bright") died while struggling to breathe. His lungs were full of blood clots. It was an awful start to my new marriage and, trying to avoid absolute grief, I spent almost all of my time doing homework with short breaks for important things, like meeting with the funeral director to plan Gabriel's funeral.

My primary care physician insisted I must have done something wrong, because babies don't just die of blood clots at 6 months. I was completely devastated. My perinatologist told me that he was certain I had a blood disorder, and asked me to come in for testing. He tested for just about everything under the sun and found several blood mutations that caused thickening of the blood. Although it was scary to hear all the risks associated with my new diagnoses, I was relived to know that my son's death wasn't my fault.

In the following year, I began having transient ischemic attacks, otherwise known as TIA's or "mini-strokes", sometimes several times a week. The hematologist I visited...
told me that women don’t have blood disorders, so I saw another, who said it was impossible that I have a clotting disorder since my sister had been diagnosed with von Willebrand’s Disease, which is a bleeding disorder. The third hematologist I saw took down my history, and halfway into it began asking very specific questions. It looked like he’d suddenly figured something out. He ran series of tests based on information he got from a seminar he’d just attended, and announced that on top of all my blood mutations, I have primary APS. When I asked why it's showing up only now, he said the pregnancy likely "jump-started" it. When I asked about what could be done about the TIA’s, he said there's nothing much to be done except to take aspirin and fish oils, which I did exactly as directed. Any time I went to the ER with TIA symptoms or chest pain, I was sent home; the ER staff told me on more than one occasion, "We'd admit you if you were a little older, but it's just so rare in your mid-twenties...sorry." This, without further testing.

Throughout all this, I worked hard to keep my diagnosis a secret. In the construction world, any perceived health danger is carefully scrutinized. Diabetes, epilepsy, an allergy to bees...some foremen were afraid to have "sickies" on their crews because they didn't want the hassle or liability.

In April of 2007, a month after I'd started with my current electrical contractor and almost two years after all this began, I had a stroke during break time at my jobsite. I was extremely fortunate to be at a large jobsite with EMTs present who knew the symptoms and called for an ambulance immediately. A hospital with a dedicated stroke center was three miles away and I was admitted and in the care of a team of doctors in under an hour. It was interesting to note that as my husband explained to the ER staff that I had been diagnosed with Antiphospholipid Antibody Syndrome, none of the male staff knew the term, but several of the female staff had heard of it; not from their schooling, but from primarily female friends and relatives who suffered from the same thing. (This excludes my female admitting physician who wrote my "strange behavior" off as "hysteria", because women don't have blood disorders. She wrote this in my chart.)

I was told that I could not have had a stroke because I'd never had a confirmed blood clot in any extremity, even though my blood pressure had been tested before on both arms simultaneously, and it was 150/90 in one arm and 70/35 in the other. I was tested for drug use and was given a psych evaluation before the director of the Neurosciences Institute and stroke center decided to go out on a limb and give me a tran cranial doppler "bubble test", because he had a hunch that there was a hole in my heart allowing smaller clots to bypass just about everything to get into my brain. The test took over an hour, mostly because (I found out later), there were "dozens of microclots" detected entering my brain before he even injected the saline.

The results were given to my hematologist, who initially refused to put me on any anticoagulants due to my age, but relented and began prescribing me warfarin the following day. I now wear a Medic Alert bracelet and am pretty open about my diagnosis to crewmates if only to advise them of dangerous symptoms, and have only had a half-dozen episodes that caused me to seek medical advice since the time of the stroke. I still struggle with some physicians and even with my hematologist, not to mention my insurance company, because APS is still widely unknown, and because of the myth that women simply are incapable of having blood disorders, strokes, or heart attacks. There is also the underlying misconception that one has to look sick to be sick, and I'm told quite often that if I just quit going to the doctor all the time for so much medication, I'd probably feel better. Must be nice to be so blissfully ignorant.

Editors Notes: Heather passed away from complications due to Chari Malformation & APS on February 8, 2012. She was 33. She posthumously won an American Solar Energy Society (ASES) award for Women in Solar Energy.

Rest in Peace Heather. ^i^
Don’t Ignore Stroke Warning Signs
Submitted by: Heidi Ponagai

When a person is having a stroke, every second counts! Certain clot-busting drugs can reduce long-term disability if they are given within three hours of when symptoms begin.

Here are some warning signs from the American Stroke Association, so you can recognize what is happening and take action right away:

- Sudden numbness or weakness of the face, arm, or leg, especially on one side of the body.
- Sudden confusion or trouble speaking or understanding.
- Sudden trouble seeing in one or both eyes.
- Sudden trouble walking, dizziness, or loss of balance or coordination.
- Sudden, severe headache with no known cause.

If you or someone with you has one or more of these signs, call 9-1-1 immediately. For more information, visit www.strokeassociation.org.


Traveling with Chronic Medical Conditions
Submitted by: Tina Pohlman

If you suffer from chronic medical conditions, here are some specific steps you can take to ensure your travel goes smoothly:

Meet with your treating physician at least 4-6 weeks prior to travel. Your physician should make sure your condition is under control. This may mean that you’ll need to have a physical exam and some up-to-date lab tests.

Confirm your immunization status. You may need boosters of some of your old vaccines. Contact the Centers for Disease Control at http://www.cdc.gov/ to find out about current conditions at your destination.

Pack enough of your medications. Make sure you pack enough medications to cover you for the entire trip, plus one extra week for any unforeseen delays. Your doctor may wish to write out prescriptions for you using generic names, as brand/trade names vary between countries.

Carry a Pocket Medical Minder. It should include:
A brief Medical History with specific diagnosis
A list of all current medications, using generic names, and their dosing schedule.

Any allergies you have to drugs and foods
If you’re a heart patient, a copy of your most recent electrocardiogram (EKG)
Your physician’s full name, address, and telephone number
A note from your physician giving clearance to travel by all modes of transportation
Your medical insurance policy number and the phone number of your insurance company

Prepare for emergencies. Plan ahead. Discuss with your doctor how to handle emergencies and contact him or her while you’re traveling.

Check your health insurance coverage. Contact your health insurance carrier to make sure you are covered domestically and overseas. If not, they can provide short-term coverage or refer you to firms that can.

Source: Delta Airlines, Inc.
Scentsy Fundraiser
By: Keri Pankratz

Support the APS Foundation of America, Inc. by placing an order through my Scentsy Website! I will be accepting orders until June 30, 2012 and then donating my commission to the APS Foundation of America, Inc. Simply visit http://www.kidsafe.scentsy.com/ and click on ‘APS Foundation of America, Inc. Fundraiser’ when entering your order!

What is Scentsy?
Scentsy Warmers use a low-watt bulb to melt specially formulated wax slowly, maximizing the fragrance time of the Scentsy Bar. With no flame, soot, smoke or lead to worry about, the Scentsy system is a safe way to enjoy more than 80 delightful Scentsy fragrances.

What is the APS Foundation of America, Inc.?
The APS Foundation of America, Inc. is the only United States nonprofit health agency dedicated to bringing national awareness to Antiphospholipid Antibody Syndrome (APS), the major cause of multiple miscarriages, thrombosis, young strokes and heart attacks. We are a volunteer run, community based 501(c)3 non-profit Public Charity organization and is dedicated to fostering and facilitating joint efforts in the areas of education, support, public awareness, research and patient services. The APSFA's Medical Advisory Team includes nationally & internationally recognized experts on Antiphospholipid Antibody Syndrome. Visit http://www.apsfa.org/ for more information!

Your Independent Consultant:
Keri Pankratz (Tina's Cousin)
Email: NoWickCandle@gmail.com
Website: http://www.kidsafe.scentsy.com/

Update on UTMB Study & Sponsorship of Medical Student Holly
Written By: Silvia Pierangeli, PhD

Under the supervision of one of our medical advisers, Silvia Pierangeli, PhD, Holly Bentz, a bright 4th year medical student at UTMB who initially rotated through UTMB during the Summer/Fall 2011 in the clinic and has shown interest in APS research, will be working on a more specific β2 glycoprotein I test kit.

Holly has made significant progress in her project. She completed what she was supposed to do. The anti-DI ELISA test is now working in our laboratory and we are about to exchange samples to confirm the validation of these studies with the group who actually described this test for the first time in London.

We are expecting to be able to write an abstract for presentation at the American College of Rheumatology and possibly a paper once we test and validate a large number of samples from patients with APS.

We are very grateful for the funds we received from APSFA. We will acknowledge the contribution when we write the abstract.

Holly is finishing medical school this semester. She learned a lot in the lab and also gave a presentation of her work in the lab in Journal Club.

For more information on the study, please see our archived newsletter here: http://www.apsfa.org/docs/APSFAVol22SumFall2011.pdf
Hello, my name is Natalia and this is my story. As a young girl I was actively involved in cheerleading which kept me busy from 5th grade to my senior year in high school. Throughout those years I had suffered injuries which caused me to become accustomed to a bruise here and there. I clearly remember having chest pains which would begin out of nowhere and last about three days; I ignored them and moved on in my life (age 16-18). Once again the pains came back but this time it lasted a little bit longer, as I decided to finally go to the Dr. I was diagnosed with stress; there were no tests and no follow up visits (age 19).

I took the doctors word for it and rewired my brain to think nothing of these sporadic pains. Three in a half years later the pain came back and shortly went away as it usually did, however two days past and it hit me harder than ever before (age 22). I was in the final lap of graduating from UCSB and my final exams to my final quarter were less than a month away. I finally gave in; one night I couldn’t sit down, sleep, move, or walk I cried in agony over the pain that was supposedly caused by stress. This is when the emergency visits began and a call for help was unanswered as I was repeatedly misdiagnosed with bruised ribs, pneumonia and the simplest of them all “we don’t know”.

It wasn’t until after my diagnosis that my battle truly began, I wanted to live as everyone else did. I pretended to be okay and the last thing I wanted was to have someone ask me how I was doing. As a twenty two year old I was lost, confused and constantly asked the unanswered question of “why me”. A year has passed and yes, I constantly struggle with my disease however, I don’t let it get in my way of achieving my goals. I was able to attain my B.A., work full time and currently moving forwards towards graduate school. I have yet let this disease overcome me however; I truly have to battle with Antiphospholipid Antibody Syndrome. I need to confront the fact that I am not like everyone else in my own unique way. Yes, I have to constantly wear a medical ID bracelet, yes, I get my lab done weekly and yes for the slightest fall, swelling or headaches I am once again walking in through those emergency doors.

It is time that I come head on with APS and truly speak out about what I have, I want to educate those that don’t know, embrace my disease and do as much change as possible. I have always been a very private person and it will definitely take time to be able to casually have a conversation with someone and talk about how I am different. I don’t want pity, I don’t want to be treated as weird or odd but I do want to make a difference. I would be lying if I told you I wasn’t scared of taking Coumadin everyday, going out and partying as much as I do, and most of all having a family with children. I don’t know what the future will hold, but I do know that after one year of ignoring it I am finally beginning to slowly open up to the truth of this very rare disease. As I reread this personal story of mine I still get very emotional knowing that I need to change in order to beat this disease, it has changed my life and it is time I make a difference both mentally, physically and emotionally.

On the flip side of this all I am pursuing graduate school in October of 2009 in Psychology which would allow me to help others in their time of need. I now try to focus on how lucky I was that I lived with this disease (genetically) most of my life and didn’t even know it, I survived for some reason. I was lucky when I was finally diagnosed because a Dr. was interested in my case and saved my life. I was lucky seeing as I was so close to suffering a stroke at the age of 22. I thank both my family and friends who have truly stuck by me and allowed me to express my confusion, hurt and anger I love you all so much.
flow, and avoids blood clots (thrombosis).\(^1\) Antiphospholipid antibodies (aPLs) of various types affect lining cells of blood vessels (called endothelial cells- ECs), platelets, coagulation-related proteins, white blood cells and chemical messages that act against or repair injury by controlling inflammation (Fig 1a and b, 1). A bruise is inflammation in action-swelling, redness, warmth, pain, and some loss of function acutely (See Inflammation Video)\(^2\). Here are some concepts about blood vessel injury I discuss with my APS patients (See Blood Clot Video)\(^3\).

Blood vessels are deep inside the body, so injury doesn’t show directly on the surface as a bruise does. Pain may be felt on the surface, as arteries, veins, and nerves are often close together. Pain sometimes stays very local or is felt in an area remote from the injury site, as these nerves also branch out, and end in different areas on skin. With a heart attack (myocardial infarction, MI), there often isn’t a pain directly over the heart, but pressure or tightness in the chest, neck or arm (Fig 2)\(^4\). With a stroke (cerebrovascular accident, CVA), one might or might not get a headache on the involved side, but might loss of sensation, speech impairment, or loss of strength.

Chemical messengers modulating blood flow via our automatic (autonomic) nervous system or by inflammation. With Raynaud’s Phenomenon, vessels in the hands and feet don’t get red, hot, and swollen, but go white and contract, and circulation is slowed. This causes pain due to ischemia (the medical term for slowly compromised circulation over time). With livedo reticularis (a lacy network of exaggerated small skin vessels), pain may result from oxygen and nutrient deprivation due to less-than-optimal blood flow in these vessels. Pain in the soft tissues may occur due to very small blood clots that can’t be imaged.\(^5\)

IECs may decrease the diameter of blood vessels by becoming injured themselves by chronic exposure to aPLs, which is called hyperplasia, rather than a large clot forming on top of them.

Suddenly, significant loss of blood flow causing severe tissue injury is an infarct or infarction. The “area of damage” can go well beyond the site

(Continued on page 9)
of a single blood clot, due to the territory supplied by that vessel. In an MI, or a CVA, pain or damage may go beyond the exact one place where a blood clot occurs. Some blood clots then break off in varying size parts and become an embolus. A deep vein thrombosis (DVT) starts in a leg vein, but may travel to the lungs or elsewhere (Fig. 3). A clot in the heart, or platelets clotted together on heart valves, may embolize to the brain. All these possibilities are important for APS patients to understand, because blood vessels go everywhere, and thus many types of signs and symptoms might occur.

Blood vessel can self-heal by creating new branches around an area of cells or tissues that have had a blood vessel injury, called collaterals. How effectively inflammation is controlled, limited, and damage is repaired, is the job of many components of our immune system: this is how one recovers heart muscle function after an MI, or brain and nerve function after a CVA.

For APS patients, adhering to their treatment regimens and working with their healthcare providers give best outcomes. Choosing not to smoke or use recreational drugs, staying hydrated, exercising regularly, and maintaining a healthy weight, improve vessels and flow. How aPLs cause changes in ECs is the focus of much ongoing research worldwide, which furthers our understanding of how injury, inflammation, and thrombosis occurs, which offers promise for novel ways to treat or prevent APS.

REFERENCES:
4. GraphicHunt www.graphichunt.com

Steps to Better Bone Health
Submitted by Todd Ponagai

Osteoporosis—a disease in which bones become fragile—is a major public health threat for more than half of people 50 years of age and older. If not prevented or left untreated, osteoporosis can progress painlessly until a bone breaks. Often, people with osteoporosis will get fractures in the hip, spine, or wrist.

Below are five tips from the National Osteoporosis Foundation that can help you improve your bone health:

- Get your daily recommended amounts of calcium and vitamin D.
- Engage in regular weight-bearing exercise.
- Avoid smoking and excessive alcohol.
- Talk to your doctor about bone health.
- When appropriate, have a bone density test and take medication.

Find out if you are at risk for osteoporosis here: http://is.gd/JFLdty

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

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

http://apsfa.flowerpetal.com

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

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

Now is a great time to start sending out your seasonal arrangements!!!

So, check out our site and support the APSFA at the same time.

Tell everyone about http://apsfa.flowerpetal.com and help us make a difference.
I wish to support the APS Foundation of America, Inc. by enclosing my tax-deductible donation to the APSFA at the following level:

- Platinum: $1000 or more
- Gold: $500 - $999
- Silver: $100 - $499
- Bronze: Up to $100

All contributions will be recognized on the APS Foundation of America, Inc website at http://www.apsfa.org

- I wish to make this donation made in honor or memory (circle one) of: __________________
- Check here if you wish to keep your donation anonymous.
- Check here if you wish to be emailed our quarterly newsletter, Antiphospho.....what?!?!

Please make your check* or money order payable to the: APS Foundation of America, Inc.

Enclose this form and your generous donation in an envelope and mail to:

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You may also send donations via PayPal to donate@apsfa.org. See our website at http://www.apsfa.org/donate.htm for more donation options.

Founded in 2005, the APS Foundation of America, Inc. is the leading United States nonprofit health agency dedicated to bringing national awareness to Antiphospholipid Antibody Syndrome (APS), the major cause of multiple miscarriages, thrombosis, young strokes and heart attacks. We are a volunteer run, community based 501(c)3 non-profit Public Charity organization and is dedicated to fostering and facilitating joint efforts in the areas of education, support, public awareness, research and patient services. All donations are tax deductible and a tax receipt your taxes purposes will be issued. Our EIN is: 20-3085295

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