# ANTIPHOSPHO...WHAT?

APS Foundation of America, Inc. Newsletter
Volume 1 Spring 2006

## Our Journey With Mystery Diagnosis

**Written by: Michelle LaRue**

Michelle with Angie & Cameron in their Iowa home

The email said, "A producer of a national TV program looking for an APS patient story had approached the APS Foundation of America." Angie's story was written down. Our local TV and newspaper had used parts of her story to promote Open Adoption. I might as well send her story to them...little did I know what we were getting into.

The first phone call with a New York producer was several hours long. She asked many questions and wanted Angie's story in great detail! Emails were also exchanged. I learned the name of the company who was producing the show. After searching the internet I found a description of the show Angie's story "might" be approved for.

Mystery Diagnosis

Type: Unscripted
Channel: Discovery Health

*What would you do if you were sick — or dying — and no one could figure out why? Would you turn to another doctor? Search for the cure on your own? Mystery Diagnosis is the acclaimed hit series that tells incredible stories of how real people wouldn't take "I don't know" for an answer — and found a way to crack the toughest medical cases.*

This described our story perfectly!

One obstacle was convincing Angie's doctors to do an interview. I gathered phone numbers and doctors were called. Her hematologist agreed to be interviewed!! His response to the producer's phone interview was, "I give Michelle credit for diagnosing Angie. All I did was confirm it." "I was very skeptical and wasn't aware of some of the APS symptoms until Michelle brought me the medical journal articles." Angie's OB/Gyn also agreed to do the show. We were getting closer to the producer's goals.

On September 16 we learned we were going to do "the show". I learned that it was not just "talking" about it, but "acting" it out too...reality TV in a big way! Now, unlike Angie, I do not like acting. This was really going to be a stretch for me. I am a facts person. Plus, I knew that acting out THIS STORY was going to be very emotional. These were very hard, scary days that we were going to be reliving. My husband was very concerned and thought it would be too hard on us to do. But some things just have to be done!

When I was 19 years old, my 18-year-old brother was killed in an industrial accident. My Mom and I often visited about how to take something so awful in our lives and find some good in it. Helping other grieving people was taking our bad and doing good. I approached Angie's illness, pregnancy, and open adoption with the same philosophy. We had to take our lemons and make lemonade!

Angie has made several pitchers of lemonade! She has been a spokesperson for open adoption AND APS. I am very proud of her! I know that she has helped several young and older women on their adoption journey. Now, she is helping the medical community try to understand a very complicated illness...hopefully saving lives along the way!

On October 19, 21, and 22 the filming was done for our segment of Mystery Diagnosis. Grueling describes these days. In a way it was surreal ... did we really live through this??? When it was actually happening we didn't examine how we were feeling...that was shoved back and getting thru it was our all we did. Now they wanted "How did you feel?" "What were you thinking?" Emotions were very raw...all but Angie had tears. Her theatre mind was in high gear and she loved every minute of it. The lights, the microphones, the camera, the crew... all of it a foreign world to us. Very thought provoking questions were asked and answered.

After a two hour interview with Angie's hematologist the producer came out laughing. She told us the doctor had described me as a "pit bull." He walked down the hallway and said, "Hope you don't mind." I hope that statement ended up on the cutting room floor! A fifteen-minute segment with three very full days of filming has to require a lot of it to end up on the cutting room floor!

Our goal is to help others. Hopefully other APS patients will benefit from our fifteen minutes of being in the spotlight.

Our episode will be premiering on March 6th, 2006 at 10 pm EST. Please check your local listings for specific times. Mystery Diagnosis is on the Discovery Health Channel.

### Friends of APSFA

Do you believe in our cause? If you do, you can now become a "Friend of APSFA". For a membership fee of $25.00 you will get our Friendship package which includes:

- Our quarterly newsletter in paper form
- 1 year 'sample' Anticoagulation log book
- Printed copy of all our Brochures
- APS Awareness pin
- Priority for answers with our "Ask A Doc" page

If you would like to become a "Friend of APSFA" please visit our website for how to do so. More information is located at www.apsfa.org/friends.htm.

## We Need Your Help!

We are in search of patient stories and Newsletter articles. If you would like to contribute something, please email us at articles@apsfa.org

We are also searching for doctors who are currently treating APS patients for our Dr. List. Please see our website for more details.

### Inside this issue:

# *Letter from the President*

*Hi Everyone! I am still in utter shock that this dream of becoming a non-profit organization is now a reality. Thank you to everyone who believed in me enough to encourage me to do it and helped me to do it and assisted me along the way. And a special thanks to my Vice President, Heidi Ponagai and my Secretary, Todd Ponagai for putting up with me. Thank you also to Michelle LaRue and Angie Abbas for taking the time and going through an emotional nightmare all over again to help us get national attention on Mystery Diagnosis on the Discovery Health Channel. And after months of waiting, I have finally been released to announce the date and time of the show.*

***Mark your calendars for March 6, 2006 at 10:00 PM EST!***

*Thank you to our Medical Advisors, Robert Roubey, MD, Tom Ortel, MD, Paul Blau, MD, Gerald Simons, RPA-C, and Virginia Tekieli Clinical Pharmacist for making sure our information is accurate and up to date and most importantly cited. But as they do in the Grammy Awards . . . I am getting the light to move on.*

*So, how did this all start? Well, ever since I was diagnosed in 2002, I found myself not having an organization to turn to in the United States. For the size of this country there should be something and there was NOTHING. I could find all the articles in the world but I couldn't find or afford to get further help. In the process of looking for my own answers people began coming to me for help directly. I was approached by another non-profit organization to work with them but after some time and soul searching I felt it was in this disease's best interest to have its very own non-profit organization.*

*There were and still are many people like me begging for help. Heidi, Todd & I partnered up. We weighed out all the pro's and con's and in June 2005 the APS Foundation of America, Inc. was formed.*

*Yes, we have had many trials and tribulations. We have also learned a lot and have met many wonderful people. But, we also have had a "leave them in the dust attitude". We have found out about the 'competitions' that really shouldn't be happening but do. Our staff is in the process of getting everyone working together for the common cause….APS awareness and education.*

*So as we grow and move forwards we hope to serve our cliental more and more.*

*We see a huge potential for growth. It is very hard not to do it all at once – but 'baby steps' are the best. So, please bear with us as we learn.*

*I hope this newsletter finds everyone in wonderful health and with a perfect INR level.*

*Sincerely,*

*Tina Pohlman*

*President & Founder*

# Do You Suffer from Photosensitivity?

**Written by: Dana Stuart**

As a part of APS, you may struggle with photosensitivity. Photosensitivity is your body's negative reaction to certain light including sunlight and florescent lighting. As with any medical condition, you might experience varying degrees of reactions that may include headaches, migraines, bouts of fatigue, rashes, and pain in the eyes. There are, however, many things you can do to cope with this pesky aspect of APS. Here are a few things to think about.

- Wear sunglasses all year round. The sun still shines in the winter and you don't have to have burnt skin to be affected by the sun's rays. Even the bright and beautiful snow can be painful to the eyes and cause headaches.
- Wear your sunglasses inside if you need to. If your employer is not willing to replace florescent lights or is unable to (as with large corporations), then you may need to wear your sunglasses in order to protect yourself. If you have an office with a window, consider purchasing a tinted plastic cover or curtains. If necessary and possible, leave your ceiling light turned off and use a small lamp. Ask your employer for help with these things. APS is a disabling disease and you have a right to work place accommodations. If you get nowhere with your employer, do this anyway. Plastic is not that expensive and it is for your own health. Also remember, your coworkers will get used to your sunglasses and when they ask you why you're wearing them inside, this will give you an opportunity to talk to them about APS. There's no need to be embarrassed about APS.

> **"APS is a disabling disease and you have a right to work place accommodations."**

- Try to keep your outside activities limited to early morning or evening time when the sun is not as vicious. If your job requires you to travel for short periods, for instance, to attend off-site meetings or conduct home visits, try to schedule these activities in the morning (if possible).
- Use sunscreen with protection against UVA and UVB rays. Make sure you look on the bottle as many sunscreens only protect against one type of ray or the other. You need protection against both. Use it all year round. It can't hurt and it will also moisturize your skin. Many people tend to forget about sunscreen when it's 10 degrees outside.
- Hats, umbrellas, and other protective clothing also help to protect against photosensitivity. There are many sites on the Internet that specialize in manufacturing & marketing protective clothing. Some products may be available in local department stores. Add something new to your wardrobe now and then; and speaking of wardrobes, don't forget your Medic Alert Bracelet.

# A Star is Born!!

### Written by: Angie Abbas

When I was five, I wanted to act. To be a star on Broadway, adored by the masses, and of course be on TV. Well, be careful what you wish for. Who would have guessed I would have made my national TV debut on a show called Mystery Diagnosis on the Discovery Health Channel?

I thought it would be a fun challenge. Finally, I was seeing the upside to a really weird disease. My family knew it would be hard to tell my very long, complicated story in great detail. I got my first dose of reality when I had to spend hours on the phone with the producers. But they were producers of an actual true blue TV show based in New York City! That was thrilling on its own.

We traveled to Minneapolis for the first of three days of shooting. I can say from experience that show biz has a lot of down time for us stars. But it was such a delight to just be able to explain APS to everyone. Plus, it was a rush for the theatrical side of my brain to have the lighting guy tell me I looked beautiful on camera. I made the producers, crew, and my doctors take a group picture as a fun little memento.

The second day of filming proved how snaky those producers were. We hung out at the hospital and reenacted some of the longest days of my life. I even gave birth to a towel while my doctor preformed a c-section on a pillow. By the end of the day, I wondered how the crew could function working such crazy hours. I was beat!

My mom fixed them a wonderful breakfast the third and final day. We made them slow down a little, enjoy Iowa on a beautiful day. They even played in the cornfield that was conveniently in our back yard. They joked around and called me child of the corn. Being from New York City and Los Angeles, even seeing a cow was a new experience for them.

I enjoyed my moment in the spotlight very much. I am proud to be a supporter of APS research and hope that I did all APS patients justice in doing the show. Plus, it is a jumping off point for my acting career.

Would anyone like an autograph?

# My Life with APS ~ Nan's Story

### Written By: Nan Smith

My name is Nan. When I was 34 years old I suffered a stroke. I was getting ready for work one morning when my left leg went out from under me. At the time I had no idea what was going on. It did not fit with my knowledge of a stroke. I spent 3-4 hours in the emergency room and by the time I was admitted I had lost all muscle function from my buttocks down in my left leg & my left arm was slightly affected. After running the usual battery of tests, the CAT scan, echocardiogram, and MRI a hematologist was called in and he told me he was going to look for rare clotting disorders. He called them "third world tests" and it would take 2-3 weeks for the results to come back. In the meantime I was transferred to a rehabilitation hospital to work on walking again.

After being discharged I saw a rheumatologist for the first time. He confirmed that I had Lupus, and, in addition, APS. APS caused my stroke. It turns out it is what caused my rash- livedo reticularis, which had started to appear about a year prior and more than likely is behind visual disturbances, dizzy spells, and seizures going back to 1993. It was good to be able to put a name to the weirdness in my life. So I got on with the business of living my life. I went back to work full time. I had to attend physical therapy 3 times a week. I had appointments with my primary care physician, rheumatologist, neurologist, and rehab medicine doctor. I had appointments for lab work.

**"APS caused my stroke."**

I've been blessed to be able to work for an agency where I can make my own schedule. I can choose, when I'm not seeing clients, to work from home or go into the office. My job requires that I travel. I drive out to see my clients either at home or at school. The stroke only affected my left leg so I was cleared to drive. So it seems that my life has not been changed so much by this diagnosis. The truth is I do my best not to let it. But I've had to learn to accept limits I would never have before. I have to take time out of my day for doctor's appointments and frequent lab work. I have to budget money for those appointments as well as the medications I have to take. Also, I am single. I have to wonder how my diagnosis will affect my chances for a serious relationship with someone. I've recently joined an online dating service and there have been a few rejections because of it.

Ultimately, though I look to the positive. I've made a conscious decision to focus on what this has brought me. My experience has made me a better therapist. I have a better understanding of what it's like to feel completely powerless, dependent on forces beyond my control. It's not a comfortable feeling. But it does give me a common ground with my clients. I can challenge them as I have done myself. It's a difficult journey, but one I feel is necessary to life. In the immortal words of Robert Frost, "Two roads diverged in a wood, and I -I took the one less traveled by, And that has made all the difference."

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**APS Foundation of America, Inc.**

## Our Mission Statement

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

# March is DVT Awareness Month

### Written By: Heidi Ponagai

March is DVT awareness month. A DVT, or deep vein thrombosis, is a blood clot that forms in a vein deep in the body. Most deep vein clots occur in the leg or hip veins. They also can occur in other parts of the body. Blood clots in the veins in the thigh are usually more serious than blood clots that happen in veins in your lower leg.

If a clot in a vein breaks off and travels through your bloodstream, it can lodge in your lung. This is called a pulmonary embolism, which is a very serious condition that can cause death.

How will you know if you have a DVT? Here are some of the symptoms and warning signs:

- Swelling of the leg
- Pain or tenderness in the leg-the pain is usually in one leg and may only be present when standing or walking
- Feeling of increased warmth in the area of the leg that is swollen or that hurt.
- Red or discolored skin.

Who is at risk for a DVT? Anyone can get a DVT. Here are some risk factors:

- An inherited condition that causes increased risk for clotting
- Sitting for a long period of time like on a long trips in a car or on an airplane
- Pregnancy, especially the first 6 weeks after giving birth
- Being over age 60 (although deep vein thrombosis can occur in any age group)
- Being overweight
- Taking birth control pills or hormone therapy, including for postmenopausal symptoms

Your risk for deep vein clots increases if you have several risk factors at the same time. For example, a woman with an inherited condition for clotting who also takes birth control pills has an even higher risk to have a blood clot.

Prevention

Preventing deep vein thrombosis depends on whether you have had a clot before or if you are at risk for developing a deep vein clot but never had one.

If you have had a deep vein clot, then you will need to prevent further clots from developing by:

- Taking your medications to prevent or treat blood clots as prescribed by your doctor
- Following up with your doctor for medication changes and blood work.

If you have never had a deep vein clot, but are in a situation that may increase your risk, be sure to:

- Exercise your lower leg muscles if you will be sitting still for long periods of time.
- Get out of bed and move around as soon as you are able after having surgery or being ill. The sooner you move around the less chance you have to develop a clot.
- Take medications to prevent clots after some types of surgery as directed by your doctor.
- Follow up with your doctor.

According to the American Heart Association, DVT occurs in about 2 million Americans every year. More people suffer from DVT annually than heart attack and stroke. Up to 600,000 patients are hospitalized each year for DVT. Know the symptoms and the risks.

Find more information at
www.apsfa.org/dvtsymptoms.htm