



ANTIPHOSPHO...WHAT?

APS Foundation of America, Inc. Newsletter

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Is Antiphospholipid Antibody Syndrome Hereditary? Should My Children Get Tested?

Written by: Thomas L. Ortel, MD, PhD

Genetic disorders are illnesses that are caused by abnormalities in genes or chromosomes. A mutation in a specific gene can have many effects on an individual person, ranging from no apparent changes to a lethal abnormality *in utero*. Decisions concerning testing one's children for a specific genetic disorder are best undertaken in consultation with a genetic counselor, to best understand the diagnostic and therapeutic implications of a specific finding.

A 'single-gene disorder' refers to an illness that is due to a mutation in a single gene. For example, hemophilia A is a single-gene disorder that results from a mutation in the gene encoding coagulation factor VIII, which results in an increased risk for bleeding. Since the gene for factor VIII is located on the X chromosome, women are generally 'carriers' for the mutated factor VIII gene (since they have two X chromosomes) and men get the disease (since they have one X chromosome). Another single gene disorder is factor V Leiden, which is associated with an increased risk for thrombosis, or clotting. Since the gene for factor V is located on chromosome 1, men and women who inherit factor V Leiden are both at risk for developing blood clots.

Many genetic disorders are more complex, however, and may be due to the effects of several genes or a combination of genetic effects with environmental factors. Examples of disorders with a more complex inheritance pattern include heart disease and cancer. Although these disorders

frequently cluster in families, there is not a clear-cut pattern of inheritance. Consequently, it is not easy to predict an individual person's risk for passing such a disorder on to one's children.



Lupus is an example of an autoimmune disorder that clearly clusters in families but does not display a clear pattern of inheritance. Family members of patients with lupus are not only at an increased risk for developing lupus, but they also may develop other autoimmune disorders, such as autoimmune thyroid disease.

Genetic studies of lupus patients and their families have identified several potential candidate genes that are associated with an increased risk for developing lupus, and some genes have been associated with specific clinical manifestations of lupus. However, no single gene mutation (or combination of mutations) is unequivocally associated with the development of lupus.

Antiphospholipid syndrome (APS) has also been reported to cluster in families, and family members of patients with APS have an increased risk for having evidence for antiphospholipid antibodies when tested. In addition, family members of patients with APS appear to have an increased risk for other autoimmune disorders, such as lupus. Well-described families with more than one affected member with APS are uncommon, however, which has limited investigations into the inheritance of APS. Consequently, no specific candidate genes have been

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March is
DVT
Awareness
Month



Patient Stories & Articles Needed!

We are in need of 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.

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!

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Letter from the President

Spring is almost here & we will be getting ready for APS Awareness Month in June. It is mind blowing to think in June we will turn 5 years old. Really, it is a milestone & we will definitely be celebrating!



I would like to thank everyone who donated to decorate our giving tree! Because of your generous donations, we were able to raise \$1960.50! The Giving Tree holds a special meaning for the members of the APS Foundation of America, Inc and the community it serves. The APSFA will be able to do a lot of awareness with those donations.

A big reminder that March is DVT Awareness Month. Many of us had some sort of thrombosis to bring us together. So, please do your part and spread some awareness about DVTs. You will find a Public Service Announcement on the APSFA's YouTube page that you can share on various social networking sites. We are also tweeting away on Twitter. You can follow us @APSFA. We will be super busy in June and we can use everyone's help. Tweet sheets are available as well.

Heidi has been busy designing again. She does an awesome job folks!! Check out our new designs on our Café Press site at www.cafepress.com/apsfoundation. She has more coming your way too. 100% of the profits goes to the APSFA. So spread awareness and make a small donation at the same time. It is a win-win situation.

We are excited that we will have a volunteer, Dana Stuart, representing us at the 13th International Congress on Antiphospholipid Antibodies. We should have plenty of news to share with you. I know Dana will represent the APSFA well. We have her loaded down with educational materials to pass out. We are a bronze sponsor for this event and are sponsoring the Young Investigator Award. I understand the competition was fierce.

We also have had our first full page professional ad printed in the Lupus Journal. We have been told it looks great. We are eagerly awaiting to see the proof from the publisher. As soon as we get it, we will share it with you. We have one more ad to go. We will share that with you as well when it is done.

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

Sincerely,

Tina Pohlman

President & Founder

APSFA Board of Directors

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Special thanks to Candy Czernicki for proof reading the articles.

The information in this newsletter is not intended to replace standard doctor-patient visits. All information should be confirmed with your personal doctor. Always seek the advice of a trained physician in person before seeking any new treatment regarding your medical diagnosis or condition. Any information received from APS Foundation of America 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.

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“Antiphospholipid by the Beach”

Written by: Silvia S Pierangeli, PhD, Chair, APLA 2010



We are organizing the 13th International Congress of Antiphospholipid antibodies in Galveston, TX, from April 13th-16th, 2010. We have secured outstanding speakers from all over the world that will contribute to an exceptional scientific program.

Importantly, this year we will have two patients/doctors forum discussion groups. Prof. Munther Khamashta (St Thomas' Hospital, London, UK) and Prof. Michael D. Lockshin (Hospital for Special Surgery, New York, NY) will conduct those sessions.

Attendance/participation is free for patients. If you wish to register please check our website:

<http://www.utmb.edu/apla2010>.

APRIL 13-16, 2010

Also patients can participate in the scientific sessions of the congress at a special reduced registration fee. Check the website for details.

Accommodation/housing registration information is also available through the website.

Schedule of Patient/Doctors Forum at APLA 2010:

Date/Time Event

Wednesday April 14th, 2010

5:00 PM – 6:30 PM

Patients and Doctors Forum: Prof. Munther

Khamashta

Date/Time Event

Thursday April 15th, 2010

5:00 PM – 6:30 PM

Patients and Doctors Forum: Prof. Michael Lockshin

If you have any questions, please do not hesitate to contact us sspieran@utmb.edu or loterrel@utmb.edu.

We hope to see you in Galveston in April!

The APS Foundation of America, Inc is proud to announce that we will have a volunteer representing us at the congress and attending the patient forums, so we will be able to give you a synopsis in our next newsletter!

Lucky Pennie

Written by: Pennie Cardoza

I was exhausted, more so than I could remember being at any other time in my life that evening in late May, 2004. So I kissed my husband, George, goodnight and headed to bed early, around 8:00 pm. I was fast asleep when I was violently awakened near midnight by what felt like someone punching me in the back. I sat straight up in bed with severe pain radiating from my back to my chest. Within a few minutes the pain subsided to a dull ache and in my drowsy state I assumed I had simply pulled a muscle while turning over in bed. I returned to a fitful sleep.

The next day I went to work, still feeling some pain and having a bit of a hard time breathing, but assuming the symptoms would improve with time. By noon, the pain in my back and my ability to breathe was actually getting much worse, so I told my boss I was feeling ill and drove myself to a nearby emergency room. Upon my arrival, I was immediately tested for a heart attack, but the tests were negative.



Pennie with her grandsons.

Within a few hours, following a battery of additional tests, I was told I had suffered a pulmonary embolism and was being admitted to intensive care where I remained for nearly a week, under sedation, while I was administered Heparin therapy to break up the clot. The emergency room doctor told me that I was one of the “lucky ones,” having survived an event that kills 50% of those who suffer it within the first minute. At that moment, I wasn’t feeling very lucky, though ... it was just one more mystery to add to the long strange medical history I had been dealing with that had both me and my family wondering if we could take much

more.

It all began in the summer of 1994. As I was leaving work one afternoon, I noticed that I was having difficulty hearing out of my left ear. Within hours, I could hear nothing at all in that ear. The next day, in a panic, I headed to the doctor’s office. My doctor could find no reason for the

hearing loss and told me it was probably a virus and my hearing would return within a few days. It didn’t. For more than a month, I was deaf in my left ear, then suddenly I woke up one morning and my hearing had returned. I was baffled. Little did I know it was only the beginning of a long and tedious journey.

Over the next ten years, I suffered from migraines, tremors in my hands, “burning” skin, muscle pain and stiffness, memory loss, word confusion, livedo reticularis, and vertigo. At one point, I even developed paralysis in my right leg and could not lift my leg to climb the stairs to our apartment. George and I also lost a child to miscarriage early on. I was seen by nearly every type of doctor imaginable, from Internist to Cardiologist to Psychiatrist, and was tested for just about every disease in the books. My diagnoses ranged from Fibromyalgia to MS to psychosomatic illness, but none of them seemed to encompass the wide variety of symptoms I had been experiencing. Although George was supportive, he was getting to the point where he just didn’t

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found that clearly identify individuals at high-risk for developing APS.

Several studies have investigated whether the presence of an inherited risk factor for thrombosis, such as factor V Leiden, in a patient with an antiphospholipid antibody, might increase the risk for a thrombotic event (in other words, two “hits” instead of just one). Although some studies have reported such an association, it has not been a consistent finding across multiple studies.

So, should a patient with APS request that their children be tested for the syndrome? In the absence of any symptoms, I generally advise that checking asymptomatic family members for antiphospholipid antibodies is usually not helpful. There are several reasons for this approach. First, antiphospholipid antibody levels can fluctuate with certain infections or



other illnesses, typically returning to normal over time. Transient antibodies are generally not associated with an increased risk for adverse outcomes. Second, some patients with antiphospholipid antibody levels that are persistently elevated do not develop thrombotic or pregnancy-related complications. In other words, the presence of an antibody does not necessarily mean the patient will have any symptoms. Third, we do not have any treatments that we currently recommend for asymptomatic individuals with elevated antiphospholipid antibody levels. Some physicians recommend a daily aspirin in this situation, but a recent prospective study showed that this did not appear to be helpful.

Family members of patients with APS who have symptoms, however, may benefit from testing for antiphospholipid antibodies, in particular, family members with thrombotic events and/or pregnancy complications. This information might be useful in deciding on the best therapy, and can therefore benefit the individual being tested. Testing asymptomatic family members prior to a high-risk period (for example, a woman considering a first pregnancy) is

generally not helpful due to the lack of clear data indicating what should be done with a positive result.

In closing, although genetics does appear to play a role in the development of APS, we currently do not have a genetic test that can be used to identify patients at risk for developing this syndrome.

For those individuals interested in learning more about a research study that is investigating the genetics of APS, please feel free to contact the author of this article (email: thomas.ortel@duke.edu). The study is currently open and enrolling!

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Does Taking Warfarin Increase My Risk of Being Killed in a Car Accident?

Written by: Al Lodwick, RPh, MA
Certified Anticoagulation Care Provider
Founder of the Warfarin Institute of America

I don’t know that I can answer that question directly. A recent report from Quebec found that taking warfarin did not appear to increase the risk of being involved in a car accident.

I have asked quite a few trauma surgeons and nurses if they have ever seen anyone who bled to death from a cut to the arm or leg and the answer is always, “No”.

So I would have to conclude that taking warfarin might increase your chances of being killed in a car crash by a slight amount, but not enough that you need to put it high on your list of things to worry about.



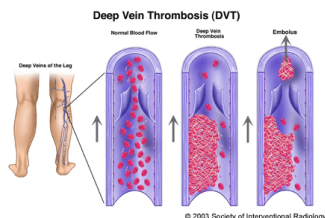
Reference: Delaney JA et al. Warfarin use and the risk of motor vehicle crash in older drivers. *Br J Clin Pharmacol*. 2006;61:229-32.

What Are Blood Clots?

Submitted by: Heidi Ponagai

Blood clots are common, potentially life-threatening, but treatable and generally preventable disorders that include two related conditions:

1. Deep vein thrombosis (DVT) – abnormal clotting of the blood in a deep vein, generally in one or more veins of the leg or pelvis, and
2. Pulmonary Embolism (PE) – when a DVT breaks free from its original site in a vein and then travels through the bloodstream into the lungs



- Cancer and its treatment
- Major trauma or injuries to the leg
- Previous DVT or PE
- Hospitalization with an acute medical illness
- Recent immobility
- Pregnancy
- Use of birth-control pills or use of hormone replacement therapy
- Family history of DVT and PE
- Obesity

Why should I be concerned about blood clots?

- Up to one million Americans suffer from blood clots every year, often resulting in hospitalization
- More than 100,000 Americans die from PE every year, which is more than the combined deaths from breast cancer, AIDS and traffic accidents Blood clots can kill quickly, or they may result in long-term pain, swelling of the affected leg and difficulty walking

DVT and PE are considered medical emergencies that require immediate care if any of the symptoms below are present:

Symptoms of possible DVT:

- Recent swelling of one leg
- Unexplained pain or tenderness in one leg

Symptoms of possible PE:

- Recent or sudden shortness of breath
- Sharp chest pain, especially when breathing in
- Coughing up blood
- Sudden collapse

What are the major risk factors for blood clots?

- Recent major surgery

DVT and PE are treated with anticoagulants, which are sometimes called "blood thinners," which decrease the blood's ability to clot. They stop clots from getting bigger, prevent new clots from forming, and prevent clots from breaking off and traveling to the lungs. Compression stockings may be prescribed to decrease the risk of venous valve damage and to reduce long-term pain and swelling.

You can help prevent the formation of blood clots by staying active, not smoking and maintaining a normal body weight. If you are scheduled for surgery or are admitted to the hospital for any reason, remember to discuss treatment and prevention options with your health-care provider.

For more information please visit www.vdf.org.

Excerpted from the Venous Disease Coalition's "Focus on Blood Clots" educational card. To get your free copy, please visit www.vdf.org or call 888.VDF.4INFO (888.833.4463). The Venous Disease Coalition is a division of the VDF.

Source: <http://www.keepingincirculation.org/articles/summer09/02.php>

The APS Foundation of America, Inc is a proud member of the Venous Disease Coalition.

For more information about Venous Disease please go to: <http://www.venousdiseasecoalition.org/>



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want to hear about my transient symptoms any longer. He was frustrated and so was I. We both just wanted our lives to be "normal" once again.

Then finally, in the months following the pulmonary embolism, I was referred to a Rheumatologist who was determined to find a correct diagnosis for me. He felt at

the age of 48, I was much too young to have experienced an embolism. He was puzzled by the fact that the warfarin I had been taking since being released from the hospital had alleviated all of my strange symptoms. He tested me for some of the more rare conditions and one of those was APS. In December of 2004, I tested positive for the Lupus Anticoagulant. Finally I had an answer. I was relieved.

Although I'm not thrilled with the idea of taking warfarin for the rest of my life, and from time to time it's a struggle to keep my INR in range, I feel happy and blessed to have the love and support of my family, friends, and the doctors who monitor my condition. Today, I am well; I have my life back.



I'm Tired of Bumping My Head

Written by: Karyn Lombana

Over this summer, I had the privilege of taking a Women's Studies course at my local community college. I took the class because, at 34 years old, I knew little to nothing about the subject, and I felt that it was about time that I learned. Our final class assignment involved picking a topic of our choice and giving a presentation on it. Because APS is something that impacts my life on so many levels, I decided on

"that the average patient diagnosed with a serious autoimmune disease had seen over four doctors over a four-year period before a correct diagnosis was made."

the topic of autoimmune disorders. My reasons for this topic were twofold: to educate my fellow classmates about APS and to try to answer a very long-standing question that has been burning at the back of my mind for years - why do some of us experience so many obstacles in obtaining diagnosis and proper care?

My own journey with APS started when I was fifteen years old. I felt pain in my groin area after an afternoon of swimming at my grandparent's pool. Thinking that it was just a muscle cramp, I just stretched a bit and tried not to worry about it. It was almost the end of the school year, and I was looking forward to a great summer. On Monday, while I was in art class, I noticed that my "muscle pull" might be more serious than I first believed. My leg had swelled considerably and turned an awful shade of purple-black, so my teacher suggested that I see the school nurse. I can still remember the horrified and concerned look on the face of my health teacher as he saw me leaving the building with my grandmother. He had a heart attack a few years before, and I think instinctively he knew that I was in trouble. This was my first experience with a clot - a deep vein thrombosis (DVT). My first DVT landed

me in the hospital for ten days, and my summer plans were put on hold as I focused on getting well. The years that followed were a blur of hospital visits, tests (they didn't use ultrasound then, so that meant lots of needles in the foot for the venograms), and doctors visits. My life stayed on hold...and to a large extent, it remains that way.

The most frustrating part of it all was that no one could

tell me WHY this was happening to me. It took about ten years for me to finally get the lab results that showed that I tested positive for lupus anticoagulant. This test, plus my history of multiple DVTs, finally gave me a diagnosis - I have APS.

Unfortunately, my experience with delayed diagnosis was not unique. One study conducted by the American Autoimmune Related Disease Association (AARDA) concluded "that the average patient diagnosed with a serious autoimmune disease had seen over four doctors over a four-year period before a correct diagnosis was made."¹

It is very easy to become frustrated as we search for the right doctor to give us the right diagnosis. We go through painful tests and procedures, and many times we receive very few answers in return. Scores of us are shuffled to doctor after doctor for years with no results, no diagnosis, and no hope of relief.

Even though I had a diagnosis, it took me eight more years to build a team of doctors that I can count on. The biggest challenge I faced was weeding out the "nonbelievers" - the doctors who tried to shuffle me off to a psychologist instead of figuring out the physiological

roots of my symptoms. The principle hurdle to good, comprehensive care was the lack of belief by the medical community...that how I felt and interpreted what my body was doing was not a product of my imagination - it was real!

I was astonished to learn how many people may be tripped up by this very same hurdle. A 2001 study by AARDA estimated that over 45% of the autoimmune patients that they surveyed have been labeled as "chronic complainers"² - in other words, they are accused of exaggerating or making up symptoms. If you assume that this percentage is an accurate reflection the experiences of all people with autoimmune disorders, the consequences become staggering - of the estimated 50 million Americans with one of the 80 or so recognized autoimmune disorders⁴, upwards of 22,500,000 people are possibly being disbelieved! And furthermore, it is estimated that up to 75% (or about 30 million) of these patients are women¹. So, one could then extrapolate that as many as 13,500,000 women have their legitimate medical concerns dismissed by doctors!

These statistics are just the symptom - they don't "diagnose" the reason for the doctors' disbelief of their patients. Once again, I found myself asking "why?" There is always the notion that some doctors just do not have enough knowledge of autoimmune disorders to identify them. If a doctor can't figure out what's wrong, maybe some doctors just assume that the symptoms must be figments of the patient's imagination. But that explanation didn't fully satisfy my curiosity. It didn't feel that this explanation wholly diagnosed the problem. I was missing a piece of the puzzle and needed to know more.

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Use of Intravenous Immune Globulin in Antiphospholipid Syndrome

Written by: Gretchen F Kunze, Pharm.D

Antiphospholipid syndrome (APS) is an autoimmune disorder that is characterized by the production of antibodies that lead to complications associated with coagulation such as venous thromboembolism (VTE) and stroke. These complications are the most common cause of morbidity and mortality in this population. Antiphospholipid syndrome is also associated with several complications in pregnancy including miscarriage, stillbirth, preterm delivery, and preeclampsia (high blood pressure in pregnancy). Anticoagulant medications such as aspirin, heparin, and Warfarin are used to reduce the risk of blood clots, however, some patients continue to experience clotting despite using these recommended therapies. Some studies have looked at the risks and benefits of using intravenous immune globulin (IVIG) in patients with APS that continue to have complications and who appear refractory to standard therapies.

Intravenous immune globulin is a blood product that has been shown to be beneficial in numerous immune system disorders. IVIG works by replacing antibodies in conditions where antibodies are deficient and can also help decrease the severity of disease by inactivating abnormal antibodies that are produced in autoimmune diseases such as APS⁵. By inactivating antibodies that are attacking an individual's immune system, there is potential to decrease complications from occurring. In the case of APS, IVIG may be able to reduce the formation of blood clots and pregnancy complications.

A majority of the studies conducted looking at the use of IVIG in APS have been in pregnant women. These stud-

ies have compared standard treatment of low-molecular weight heparin and aspirin with IVIG in the prevention of complications leading to pregnancy loss. Although results have varied, most of the studies have found that standard treatments result in higher rates of live births compared to IVIG^{1,3,7}. Positive results were found when IVIG was used in a 32 year old female who developed low platelets, elevated liver enzymes and progressive stroke symptoms a few days after preterm delivery. The patient was initially placed on low-dose aspirin and heparin for her stroke, but her condition continued to deteriorate despite these therapies. IVIG was started and given for three consecutive days and resulted in rapid resolution of stroke symptoms as well as increased platelet count⁴. Although IVIG proved to be beneficial in this case, IVIG continues to be a last line therapy option in patients with APS due to inconsistent study results.

Because IVIG is a blood product, there are several risks associated with its use. Hypersensitivity reactions, infection, renal failure, and thrombotic events have all been associated with IVIG. In addition to these potential adverse reactions, IVIG therapy is very costly. Yet another thing to consider is time. IVIG is administered by infusion, and several hours are often required to receive this therapy.

IVIG is an effective treatment option in many different disease states. Although the potential for IVIG to be beneficial in APS seemed promising, mixed study results have proven otherwise. Given the lack of strong supportive evidence, cost, time, and risk of adverse events, IVIG will continue to be a last line therapy option in patients with APS. At this

time, the risks appear to outweigh the benefits in this population of patients.

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We would like to say thank you to everyone who submitted photos and/or patient stories during our call out for "Faces of APS." The ad has been created and will premiere in the *Lupus Journal* at the 13th International Congress of Antiphospholipid Antibodies.

We will also be using the page as part of our Awareness materials for June and it will be included in the next downloadable newsletter! The photos that were not used will be featured on the APSFA website to continue the "Faces of APS" theme and should appear for June, which is APS Awareness Month!



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The deeper I dug, the more I realized that things might be more complicated than lack of training or ignorance on the part of a doctor. I asked myself, can societal norms (like how society views class, race, age, disability, and gender) also impact how we are treated as patients? Given that the majority of those affected by autoimmunity are women, I started with what I had learned already in class. A major component of Women's Studies is the exploration of history and ideologies that have shaped our society. These ideologies eventually become societal norms, and the norms are often used to distribute power to certain groups of people while limiting power to others. This can impact how we, as individuals, are treated and how we treat others. Dr. Jennifer Woods comments that, "historically, women have been placed in subordinate positions within society."⁶ Therefore, it is logical to think that our society's views of women may play a part in how female patients in particular are perceived and treated (literally and metaphorically) by doctors.

An article from the Boca Raton News dated June 12, 1979, illustrated the prevailing attitudes of some doctors at that time and how they treated their male and female patients:

He complains of chest pains and gets a cardiac work-up. She reports chest pains and gets little more than a patronizing pat on the back. His headaches are taken seriously. Hers are dismissed with a pep talk. He wouldn't waste a doctor's time unless he had a legitimate physical reason. She is bored and really looking for emotional support or a father figure.²

The attitudes of some doctors have not changed all that much in the 30 years since. The women's health forum, Estronaut.com, explains that "many women experience the problem of having their medical concerns dismissed by their own doctors as being 'all in your head.' Physicians more often label women patients' complaints as emotionally based...This...gets confused with the source of the problem by some doctors and health providers, *because of their own learned gender biases.*" (italics added)⁵

I do not write this with the intention of labeling all doctors as sexist nor am I implying that gender bias is the only reason why we female APS patients may be disbelieved by our doctors. Sexism is just another piece in the diagnostic puzzle that deserves our attention and consideration. The fact remains that the institution of medicine – the system by which doctors are trained and in which they work – has a history of allowing

societal norms to affect the treatment of women⁶ and knowing that fact may be the first step to understanding and changing some doctors' perceptions of their female patients.

It is my hope that we all continue to work together with the medical profession with the goals of mutual respect and education. A large part of this involves creating and maintaining an open dialogue with our doctors regarding what **we feel we need** as patients. We cannot allow ignorance, lack of respect, or bias to frustrate us into feeling that there is no hope...that we must settle for (and even appreciate) whatever small crumbs we can get and accept the notion that inadequate or sub-standard treatment is "normal" (and all the while smiling blithely as if nothing is wrong). We need and deserve better! We will bump our heads against a lot of brick walls in the process. Some doctors will refuse to treat us because we are "uncooperative." Others will continue to try to pass us off to psychologists. But I have to believe that some doctors will listen. Remember, many feminist women in the early 1900's were labeled as "crazy" and "hysterical" because they were demanding change³. Yet, they persevered and affected changes that women still benefit from today. Likewise, I think, with persistence, we, too, can pave the way for better and more compassionate care for all those with APS who follow us.

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8 Ways To Encourage a Chronically Ill Mom

Written by: Lisa Copen

Mommy moments come in all forms of days at the park, backyard BBQs, or meetings at the pool. They are a great time to get to know other mothers and share activities as well as advice. But

as the number of women who live with chronic illness continues to grow, so does the spontaneity of the fun of these mommy moments. For example, ac-

According to the National Fibromyalgia Association, fibromyalgia (FM) experts estimate that about 10 million Americans and approximately 5% of the population worldwide suffer with FM, one of the fastest growing auto-immune diseases in the USA. I recently attended an adoptive mom's playgroup and within this niche group, three out of the six of us had chronic illnesses. Being aware of a friend's limitations and challenges, acknowledging them, and just asking questions, can make a huge impact in their ability to participate and feel comfortable with their peers.

1. Ask what time of the day is good for play-dates or activities. This can vary from season to season (weather affects it a great deal); and also from one illness to another. For some moms, mornings are good and afternoons are exhausting; for others it's the other way around.

2. Be flexible and don't make her feel guilty if she must cancel. Having a chronic illness means each day is unpredictable. Last week I

took one step and my knee was locked up for four days. I winced in pain as I did heat and medication therapy while my husband worked at home. All my plans were cancelled and I had no advance notice.



may be difficult if not impossible so take the elevator with her. When she walks keep a pace with her and realize she may have to take rest stops even while walking small distances. Chase after her kids and let her have a few minutes of rest. Standing for long can also be challenging. What looks like a short line for the carousel may be impossible for her to withstand. Offer to stand in line and let her jump in later.

4. Ask polite questions about her illness, such as "what is your greatest challenge?" Avoid telling her about the cures you've heard for her illness; the products you may sell that could help her; or about your mother's cousin's sister who has the same illness but still manages to raise five children and work full-time.

5. Be aware of simple things that may be difficult for her. For example, if you go to the beach, you may want to ask her if she would like to be dropped off while you find a parking spot; she may not be able to sit on the ground so bring a few lawn chairs so she isn't the only one two feet above the rest of your friends. She will likely be limited in her sun-exposure. She may not be

able to carry as much picnic items as you can from the car. While you don't want to make her feel helpless, nor does she want you to make a big deal out of it, just be aware that she may need some extra considerations.

6. Don't assume that she can take care of your children, even for five minutes, unless she volunteers. Child-caring is exhausting and caring for her own may be zapping her of the little strength she already has. Plus, if your kids are prone to run out into the street, realize that she may not physically be able to chase them.

7. Plan activities that she can participate in. While you may love your stroller exercise groups, and mommy and me gym classes, these may not be options for her. Ask her what kinds of things she likes to do and then join her for these. Keep the activities under three hours; while you may spend six hours at the zoo, affirm that you completely understand she needs to get home. Don't say, "a little more exercise may do you some good!"

8. Lastly, tell her what every mom longs to hear: "I don't know how you do it. I really admire your perseverance and strength."

Lisa Copen is editor of HopeKeepers Magazine, hopekeepersmagazine.com a consumer publication for those with chronic illness, and founder of Rest Ministries, www.restministries.org. Daily devotionals, a free magazine, dozens of e-groups, books by Lisa, including "Why Can't I Make People Understand?" <http://www.comfortzonebooks.com>

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