ANTIPHOSPHO...WHAT?

APS Foundation of America, Inc. Newsletter
Volume 6 Summer 2007

I Have the Lupus Anticoagulant, But I Don't Have Lupus?

Written by: Thomas L. Ortel, MD, PhD

Lupus is a chronic inflammatory disorder that can affect almost any organ of the body. Common clinical manifestations include arthritis, skin rashes, and fatigue. Certain laboratory findings are also frequently found in patients with lupus, including evidence for anemia and low platelet counts ('thrombocytopenia'). Patients with lupus also have some very characteristic *auto*antibodies, such as antinuclear antibodies ("ANA"), antiphospholipid antibodies (which include the lupus anticoagulant), and antibodies to DNA, the molecule that makes up our genes ("anti-DNA antibodies"). Autoantibodies are antibodies that bind to the patient's own proteins, cells, and tissues, resulting in the various symptoms that these patients develop.

The lupus anticoagulant is a particular type of antiphospholipid antibody that is detected by using certain laboratory tests that measure blood clotting reactions. It differs from an anticardiolipin antibody on the basis of how it is detected, but both lupus anticoagulants and anticardiolipin antibodies are antiphospholipid antibodies. The lupus anticoagulant is associated with an increased risk for thromboembolism ('blood clots') affecting either arteries (causing strokes or heart attacks) or veins (causing deep vein thrombosis or pulmonary embolism). In some patients, it is associated with recurrent miscarriages. Although this autoantibody is called a lupus anticoagulant, the name is actually inaccurate and confusing.

First, although the '*lupus*' anticoagulant was first described in several patients with lupus, most patients with lupus anticoagulants actually don't have any of the other clinical manifestations of lupus. These patients may have blood clots or recurrent miscarriages, but they don't have lupus. They are referred to as having 'primary antiphospholipid syndrome', or primary APS.

> **"…although the '*lupus*' anticoagulant was first described in several patients with lupus, most patients with lupus anticoagulants actually don't have any of the other clinical manifestations of lupus."**

Second, clinical laboratory testing of the blood from a patient with a lupus '*anticoagulant*' is frequently abnormal and looks like the patient is taking an anticoagulant ('blood thinner'). If not carefully evaluated, the physician might mistakenly think that the patient is at risk for bleeding. In contrast, these patients typically do not bleed, but are instead at a higher risk for thrombosis.

Consequently, the lupus anticoagulant is identified in many patients who do not have lupus, and it is not an anticoagulant! There have been recommendations to change the name, but none of the alternative names have been accepted. Whenever telling a patient that they have a lupus anticoagulant, it is important to clarify that this does not mean the patient has lupus, nor that they are taking an anticoagulant!

Do the memory issues and brain fog of APS affect you? If you are having a hard time remembering to take your evening, afternoon or even morning pills, set the alarm on your cell phone or watch to go off at the time you need to take your pills.

Now you only need to remember why your alarms are going off at odd hours of the day…

Friends of APSFA

Do you believe in our cause? If you do, you can now become a "Friend of APSFA". For a 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

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 *need* 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

Fall is upon us already and before long we will be getting ready for Christmas. Where has the summer gone?

June was APS awareness month and we did get some press about Antiphospholipid Antibody Syndrome (APS). We have had some great some great feedback from these articles and hope to see more published in the near future. You can find the articles located here: http://www.apsfa.org/links.htm#catid43789 Thank you to everyone that helped make this year a success! Next year will be bigger and better!

We have also launched an informational video on the basics of APS. You can watch the video in its entirety on our home page. We have had many hits on this video and have gotten a lot of great feedback. Watch our webpage for more informational videos to come.

We are collecting articles for our newsletter. Article topics can be from how APS affects you, poems you have written, your favorite hobby, tip and tricks that help you get through your day, to your favorite recipe. We are also taking book reviews of publications listed on our suggested reading page at: http://www.apsfa.org/publications.htm. If you have an idea that's not listed here and are not sure if it would be appropriate, please drop us an email at articles@apsfa.org.

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

Sincerely,

Tina Pohlman

President & Founder

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I Am Thankful ~ Bob's Story

Written by: Bob Clift

Although it isn't anywhere near the third Thursday of November, I am very thankful. My mother frequently demonstrated, "giving thanks in all circumstances," during her losing battle with recurrent breast cancer, by constantly looking for things to be thankful for in the midst of adversity. She taught me that everything and every person has a purpose, and that every circumstance can be endured and overcome. Her death at 49 years of age was the most difficult experience I have had to deal with, and being diagnosed with APS a year later, made 1989 a year of trial and growth that has helped make me who I am today.

My own medical history is one of blood and broken bones. I was born a month early by Caesarian when my mother abruptly began bleeding. When I was 5 years old, I fractured my wrist riding my bike too fast after the training wheels had been removed. Then when I was 8 years old, I sustained a serious skull fracture and whiplash from falling backwards off a ladder into a construction fence. During subsequent treatment, I was given anti-convulsants and other drugs that severely lowered my white blood cell count, requiring a period of follow-up visits to a pediatric hematologist. Then just before I turned 16, while skiing too fast, I suffered a compound spiral fracture to my lower left leg. This was in February. My mother passed away in May. And in October of 1989, gangrene caused by arterial blockage began to affect three toes of my left foot. But when those wounds healed the next February, the surgeon considered me healed: case closed. Not convinced that the cause of my gangrene had been discovered, my dad insisted on a visit to a university clinic while we were in the US during the summer of 1990 on other business. There, after extensive blood tests and an arteriogram of my left leg, I was diagnosed with Lupus Anticoagulant and started on therapeutic doses of Warfarin. I was 17 years old.

Over the next ten years, I settled into a routine of daily Warfarin and bi-monthly blood tests. And except for a tendency to develop scars even from minor cuts, it was easy to forget that I had a life-threatening autoimmune disease. But then in April of 2001, I began to notice being short of breath during strenuous exercise, and a lung scan confirmed that blood was not reaching a majority of my right lung. A cardiologist suggested inserting a filter into my inferior vena cava, to prevent clots from the legs moving into the upper body. Other than that, he said, the only other thing that could be done involved major surgery to physically remove the clots, but as long as I could still function normally, it was not worth the risk. However, even though I continued on Warfarin, the clots progressed, and I had to be hospitalized in February 2006 for extreme shortness of breath. During that hospitalization, a chest sonogram indicated that I had developed pulmonary hypertension, a condition of high back pressure on the heart, caused by blocked arteries in the lungs. Since there were viable medical options to reduce this pressure on my heart, I knew the time had come for "that surgery". So, in May 2006 I underwent a pulmonary thromboendarterectomy, which involves removing the inner membrane of the artery wall, pulling all clotted material out with it. Although it took many months to recover from the effects of open-heart surgery, I am thankful that I have a new lease on life.

I am thankful to be alive.
I am thankful for a quick diagnosis.
I am thankful for informed and cooperative doctors.
I am thankful for adequate medical insurance.
I am thankful for a supporting family.
I am thankful for this support group.

The terms of that lease include more frequent visits to my local internist and periodic visits to a handful of distant specialist. APS has become a disease to be guarded against, no longer a mere inconvenience. But I am thankful that I can receive proper care even here in rural Japan, and that APS can be controlled. However, my experiences have taught me that life is fleeting, and therefore I must make the most of the opportunities I am given.

Legacy ~ A Poem

Written by: Theresa M Akard-Smock

I chose peace when I recognized conflict,
I chose love when I recognized hate,
I chose life when I recognized death.

I cried because I was helpless and learned of hope,
I cried because I was in pain and learned of comfort,
I cried because I was alone and learned I was surrounded
by the loving souls on this path before me.

They whispered strength and calmness into
my shattered pieces I lay trying to collect,
They turned my minds eye away from reliving
my tragedies as each had struck,
They hushed my lips from screaming, "Why!"
They focused my thoughts onto the rebuilding of me
as a loving soul worthy of their tender touch,
Worthy of life and respect gained from just being me drawing breath.

Now I breathe and look at life,
Now I claim my rightful place,
Strength, choice, and wisdom won,
I stand to teach, I rise to lead, realizing the battle as newly begun.
No weapons brandished, no siege called,
I stand firm on the field of bow and please,
Refusing to bend or scrape.
Every action I undertake or reject gives new perspective,
Seeding the field with my belief, my integrity,
Honoring all before me, respecting all on the path behind me,
Who may never know my face, but who will know and benefit from
my struggle to be a woman with a voice.
On the field I was expected to silently work,
To them I leave the legacy to the little patch
I owned,
And the tools to expand the claim.

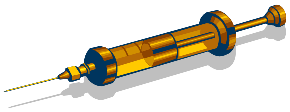
What Is the Long-Term Safety of Lovenox?

Written by: Kai Davids, Pharm.D Candidate
University of Colorado Health Sciences Center
Reviewed by: Al Lodwick, RPh, MA

Lovenox (enoxaparin) is an anticoagulant, meaning that it inhibits the formation of blood clots. Lovenox is a low-molecular-weight heparin (LMWH) that is newer than unfractionated heparin. Low-molecular-weight heparins (Lovenox, Fragmin) are often preferred over unfractionated heparin in both the inpatient and outpatient settings since patient responses to LMWH are more predictable.

Most patients that require long-term anticoagulation are treated acutely with a LMWH and then transitioned to warfarin. However, some patients require long-term anticoagulation with a LMWH which brings up the question of safety with long-term use of LMWH.

Data on long-term safety of LMWH is lacking. This is due in part to the fact that they have only been used in the United States the 1990s. In addition, most patients needing LMWH only receive short-term therapy. As a result, there have been only a small number of patients on which to base decisions regarding its long-term use.



It has been demonstrated that long-term unfractionated heparin use can cause low potassium in the blood, elevated liver enzymes, and osteoporosis. Since LMWH and unfractionated heparin are similar, some question whether LMWH could also cause the same effects. A chief concern with long-term LMWH use is its potential to cause osteoporosis. It appears that long-term exposure to LMWH does cause a decrease in bone mineral density (BMD). One study found that there was a greater decrease in BMD after 2 years of treatment in patients who were treated with Lovenox than with patients treated with acenocoumarol, a drug similar to warfarin used more in Europe than the rest of the world.. In light of this, some experts recommend bone density studies before starting long-term LMWH therapy and annually thereafter.

Reference: Wawrzynska et al. Changes in bone density during long-term administration of low-molecular weight heparins or acenocoumarol for secondary prophylaxis of venous thromboembolism. Pathophysiol Haemost Thromb. 2003;33:64-47

Change Isn't Just What's In Your Pocket

Submitted by: Tina Pohlman

We all experience change, whether it be a change in our personal or professional lives. For some people, experiencing change is very overwhelming. No matter what type of change you are experiencing, there are always ways to cope.

Empty nest (a condition some parents experience when their children move out of the home.)

- Allow yourself to experience emotion.
- Get to know your spouse again and enjoy the newfound peace and quiet of your home.
- Take up hobbies.
- Give yourself time to adjust. Talk to other empty nesters.
- Maintain proper diet and exercise to keep your energy level high.
- E-mail or give children pre-paid calling cards and plan a time to talk each week.
- Prepare care packages for your children.

Adult-child to adult-adult relationship

- Keep the lines of communication open.
- Encourage independence and responsibility.
- Respect your children's boundaries.
- Set realistic expectations of your children.

Change in the workplace

- Make your work area pleasant and comfortable.
- Learn new skills that may help you in your future career.
- Maintain contact with former coworkers who can help you cope with change.
- Do your homework! Research your new company and ask questions.

Change in living situation

- Plan ahead. Make sure you have all of the necessary resources to complete your move.
- Allow yourself to experience emotions.
- Plan good-byes and keep in contact with old friends and family.
- Become familiar with your new town; take a day to explore what your new area has to offer.
- Find ways (hobbies, sports, church groups, etc.) to connect with your new area.

Retirement

- Keep in contact with friends from work.
- Spend time with old friends, or find new friends to keep meaning in your life.
- Stay physically and mentally active — seek out volunteer opportunities.

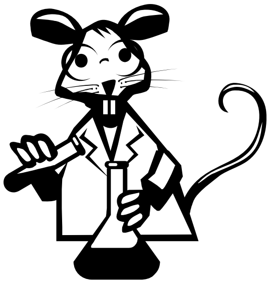
To cope with major life changes:

- Focus on the known — focusing on the known instead of the unknown will lessen anxiety.
- Identify patterns — this will help you develop coping skills to deal with future changes.
- Anticipate change — preparation helps to avoid obstacles and provides more options to explore.

Source: Gundersen Lutheran: Prevention Connection Vol. 5, Issue 3, Fall 2006

The Legend of Warfarin—It's Rat Poison Isn't It?

Written by: Al Lodwick, RPh, MA



During the late 1800s the pasteurization of milk became common. About this time, too, the railroads began to provide rapid and reliable transportation over long distances. Cities were also growing to huge population numbers. As a result dairy farms became a large industry This was particularly true in Wisconsin - America's Dairyland. Corn and alfalfa hay were the primary crops fed to cattle. Eventually there was not enough cropland to grow these crops. By the 1920s, it became necessary to find a crop that would be nutritious for the cows and grow on marginal soil. Sweet clover was imported for this purpose.

The smell of new-mown hay is due to a chemical called coumarin. Sweet clover contains a lot of coumarin. In addition it has more moisture than alfalfa. Consequently when the sweet clover was stored in silos, the heat and pressure caused the coumarin molecules to link up with each other into a chemical that was later named dicoumarol.

Dicoumarol is an anticoagulant. When the hay from the sweet clover was fed to the cattle the following winter the dicoumarol reduced the ability of the blood of the cattle to form clots. Consequently many cattle died from internal bleeding.

A Wisconsin dairy farmer named Ed Carlson became very irritated over the death's of his cattle. He loaded a dead cow and a milk can of unclotted blood into his truck and drover 100 miles in a blinding snowstorm to the University of Wisconsin in Madison. When he arrived he discovered that, "Them damn professors don't work on Saturday.". So he unloaded the dead cow and the milk can of blood, along with a note, on the steps of the agriculture school building. On Monday morning when Dr. Karl Paul Link, a microbiologist, came to work he discovered the items Mr. Carlson had left. Dr. Link suspected that there was a previously unknown bacteria causing an infection that led to bleeding. Eventually it was discovered that dicoumarol slowed the blood clotting process.

Dr. Link was not a medical doctor; he worked in the agricultural field. His interest was increasing farm yields. With this in mind, he turned to rodent control with his new chemical. In 1945 he was able to produce the chemical called warfarin. The name came from the Wisconsin Alumni Research Foundation, the organization that funded the research. During 1951 the Korean War was being fought. A Navy recruit who evidently did not want to go to war ate about a pound of the warfarin rat poison in a suicide attempt. He was treated with vitamin K and made a full recovery. This led to the realization that warfarin could be used in humans to treat blood clots.

In 1954, warfarin was approved as a human drug. In 1955, President Eisenhower had a heart attack and was given warfarin. However, it wasn't until about 1990 that warfarin management became more of a science and less of an art. We now have several people alive after taking warfarin for up to 47 years. Many are doing well after 30 or more years on warfarin.

PLEASE NOTE: This is not just a fun story -- there is a report of a woman who was not taking warfarin but spread a warfarin-type rat poison weekly without wearing gloves or washing her hands afterwards. She evidently absorbed enough warfarin through the skin to cause a brain hemorrhage. (A drug interaction may also have been involved.) The authors state that there are three other cases of absorption of warfarin through the skin causing coagulation problems. Reference: Abell TL et al. Cutaneous exposure to warfarin-like anticoagulant causing an intracerebral hemorrhage:a case report. J Toxicol Clin Toxicol 1994;32:69-73.

To read more about warfarin, please see the Warfarin Institute of America's website at: http://www.warfarinfo.com/ .

From the APSFA FAQ Page

If my antibodies become negative, should my doctor stop my anticoagulant?

Not necessarily. Sudden stopping of an anticoagulant could, under some circumstances, have extremely disastrous results. And as I have often cautioned medical students: While laboratory assays are invaluable both in diagnosis and in following treatment, the physician should treat the patient, not the lab test.

How to handle this situation is very much a clinical decision, based not only on blood values but on the doctor's experience, familiarity with the patient's history, examination and, to be frank, gut feelings (medicine is an art as well as a science).

It should be noted, too, that in such a situation, the physician may feel that further lab tests should be ordered, since there are additional proteins (unrelated to APS) involved in the clotting process. Assessing the levels of these elements may be helpful in clarifying the picture.

Nattokinase

Written by: Stephan Moll, MD

Nattokinase is a soybean food content, produced by the bacterium Bacillus subtilis (natto) during fermentation of soybeans. It is a 275 amino acid protein. It is also called “Subtilisin NAT”. Two types of Nattokinase preparations are commercially available: (a) NKCP® by “Daiwa Pharmaceutical Co” and (b) NSK-SD™ from “Japan Bio Science Laboratories”. They are produced by different methods, and, thus, their make-up is somewhat different, but they both contain Nattokinase, which is the compound thought to have clot-dissolving abilities.

> **“Nattokinase is not a substitute for Warfarin! If you take it – don’t count on it having any clinical effect. It has also not been studied regarding its safety profile, particularly when taken together with Warfarin or aspirin. ”**

There are research data that show that Nattokinase increases the clot dissolving activities (= fibrinolytic activity) of blood in the test tube. Nattokinase does this by two mechanisms: it inactivates a protein called “plasminogen activator inhibitor-1” (PAI-1) and directly degrades the structural protein called fibrin, that makes up clots. Oral intake of Nattokinase has been shown to suppress clot formation and enhance clot resolution in animals.
However, to my knowledge, only one clinical study has been performed and published assessing whether Nattokinase has any real benefit in the prevention of blood clots in humans. In that study Nattokinase or placebo were given to individuals prior to long distance (7-8 hours) flights. Of the 92 individuals in the placebo group 7 developed a clot, all without symptoms, discovered by ultrasound; of the 94 individuals in the Nattokinase group none developed a clot. Main flaw of the study, limiting the usefulness of its conclusions, is, that the publication does not indicate whether this was a double-blinded study, or, at least, an investigator-blinded study. A non-blinded study has the potential for bias, limiting the validity of its findings and conclusions.

I think, it is fair to conclude at present that Nattokinase may have some potential to protect from blood clots. However, it has not been appropriately studied in humans. This is true for either one of the two commercially available Nattokinase preparations. Other health care professionals have similarly concluded that there is an absence of data at this time that Nattokinase has clinical effectiveness. Any comments and conclusions that “it is effective in preventing blood clots in humans” are, at present, speculation, and any claim that one should consider “using Warfarin and Nattokinase together and titrate the Warfarin downward” to “decrease the harmful effects of Warfarin while maintaining a safer level of anticoagulation with the positive effects of nattokinase” are clinically and scientifically unsound. Nattokinase is not a substitute for Warfarin! If you take it – don’t count on it having any clinical effect. It has also not been studied regarding its safety profile, particularly when taken together with Warfarin or aspirin. The FDA concluded in 2002 that there is no “adequate basis to conclude that NKCP [Natto extract] containing 0.01 % of Nattokinase enzyme is reasonably expected to be safe” and that “there is inadequate information to provide reasonable assurance that such ingredient does not present a significant or unreasonable risk of illness or injury”. Furthermore, the FDA has warned as recently as September 21, 2006, that unsubstantiated and illegal claims are being published about the effectiveness of NSK-SD Nattokinase.

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This article is adapted from a Nattokinase Q/A published by Dr. Moll at www.fvleiden.org/ask/70.html.

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What Your Spouse Doesn't Know Can Kill Them: Discovering My Wife Has APS

Written by: Tony Gilbert

"I can't breathe!" she gasped, reaching for her chest with one hand while attempting to steer the car with the other. Her face turned white as she winced in pain. "What's wrong?" I was terrified. What was this- a heart attack? My wife pulled the car over, still struggling to breathe. I immediately did what most husbands would do in my situation; I panicked! Realizing panic was a luxury I couldn't afford, I gently pulled my wife into my seat and eased into the driver's seat. Luckily, we were only ten minutes from a local hospital. I made the trip in five. Sliding to a stop, I jumped from the car and rushed my wife through the Emergency Room doors. "Everything is going to be fine." I reassured her, but she knew my broken smile too well and I am a horrible liar. She knew I was just as scared and uncertain as she was. Pulling my wife behind me, I began explaining the situation to the Triage Nurse. She told me to have a seat and someone would be with me in just a moment, I lost what little calm and sanity that still resided in me. I began screaming "My wife is having a heart attack, in a moment, she might be dead!" Thankfully, I didn't have time to examine the reality of my statement. Shortly there after, a doctor dressed in a white lab coat and two rather large security officers came for my wife and I. They understood my temporary insanity and began treating my wife immediately. The doctors were puzzled. This was not a heart attack, but something different. "I don't care what it takes, you fix her!" My speech was almost an incoherent growl by this point. The security guards escorted me to a small waiting area nearby where I began the playing a game I never was very good at, the waiting game.

I took an emergency leave of absence from work and relatives looked after our three children while the two of us spent night after night in the hospital. I left her side only to use the bathroom and shower. Just as the hospital recliner seemed to feel like home, an answer came. So after a week long hospital stay, several specialists, multiple incorrect diagnoses, a myriad of tests, and a potentially life threatening procedure, we learned the truth. A blood clot had formed behind my wife's knee, broken free, travelled up through her leg into her chest, and found its way into one of her lungs, causing her sudden attack in the car. A Pulmonary Embolism was the cause of my wife's near death experience, not a heart attack. Although, I swear I almost had a heart attack myself that day. Soon after, my wife was diagnosed with APS. The woman I vowed to love and protect was now being attacked right under my nose, by an invisible killer. I can explain my exact feelings in one word- helpless.

Today, our lives are very different. I feel like a little boy teeter-tottering back and forth on a see-saw, some days are up and some are down. On good days, my wife is her vibrant, energetic, self, determined not to let anything stop her. It's on these days, I lie to myself and pretend she's not sick, but again, I am a horrible liar. On the really bad days, she is a prisoner in her own body, she can't get out of bed without help, recall a conversation we had an hour earlier, or even walk up a flight of stairs without excruciating pain. I would give anything to trade places with her. APS is the worst type of thief. It takes away one very simple, yet priceless gift, freedom. People who suffer from APS can become slaves, held captive by exhaustion, vertigo, memory loss, medications with dangerous side affects, and very real pain. The best gift you can give a loved one with APS is support and understanding. Granted, it's not easy on my wife's bad days, I take care of her, the children, the house, the dogs, and whatever crisis that arise. These responsibilities must all be managed during a six day work week where I work eight to ten hour shifts each day. Sometimes sleep just doesn't fit into my schedule. In the end, there is only one reason I struggle through the exhaustion. She is lying next to me, peaceful and beautiful while she sleeps. Educate yourself and those around you, we all fall down, it's who you help up that makes you a hero.

A Study of the Genetics of Antiphospholipid Antibody Syndrome

Written by: Melissa Hall

Rare Thrombotic Diseases Consortium

We have recently opened a study investigating patients with familial APS. We are looking for families where an individual has APS and one or more family members also have APS. We are also looking for families where an individual has APS and one or more family members has another autoimmune disease, including lupus, type I diabetes, rheumatoid arthritis, juvenile rheumatoid arthritis, multiple sclerosis, autoimmune thyroid disease, psoriasis, inflammatory bowel disease (Crohn's or ulcerative colitis), scleroderma, Sjogren's syndrome, polymyositis, myasthenia gravis, undifferentiated connective tissue disease, or idiopathic thrombocytopenic purpura.

If your family has one or more members with APS or another autoimmune disorder, your family may be eligible to join the study.

For more information or to enroll your family in this research study, please visit our website or contact the research coordinator:

Melissa Hall
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919.681.9565
www.RareDiseasesNetwork.org/RTDC

Note from the APSFA—If your situation falls within the parameters of this study, we urge you to enroll your family. The only way we can learn more about the genetics of APS is to help the researchers whenever we can.

Redefining Self Care

Written by: Roz Laraway, MS

Clinical Therapist, Franciscan Skemp Healthcare

"The only thing we have to fear is fear itself." ~Franklin D. Roosevelt

These words have the ring of truth. This is why they are so often quoted and remembered over the years since FDR reassured a frightened nation that people have within themselves the capacity to walk on and move forward in spite of being afraid.

It seems that being aware of fear as only one small part of us, as an emotion we feel which does not have to define who we are or what we do, is an important first step in learning to cope with any new challenge in our lives.

> **"Here's the deal. You are made up of a body, a mind, and a spirit. When any one of these is in turmoil, it affects the others."**

When illness strikes, first it must be understood. We have to figure out what exactly APS is, what to do about treating it, learn how it might effect everyday life, and begin to plan for adjusting and accommodating when necessary. In one sense, those are the easy parts because those are things we do intellectually and behaviorally. Most people don't realize this, but it's the emotional and spiritual struggles that can really take the sparkle out of our eyes, the fun out of life, and can even rob us of hope.

If you think about it, making an adjustment to how you do a specific task, for example taking medication on a schedule, requires thought and planning, but is not an overwhelming task. Problems arise when you have no motivation to do much of anything, or when you can't get enough sleep and are chronically exhausted, or when making the effort to take that medication on time seems pointless. Now something else is happening. Depression is creeping in and we are emotionally struggling because of it.

Anxiety also can become a problem. It can become a chronic kind of worrying, or it sometimes fills our mind with panic, or leaves us feeling paralyzed and outside of the flow of life. Another common problem is that anxiety often robs us of the blessed elixir of sleep, wonderful restful healing sleep. We can be quick to anger, feel more stressed than usual, and distracted as if there are two television channels tuned in our mind at the same time. Anxiety can steal our peace of mind, our contentment and confidence in our future.

Spiritual doubt takes many forms. We question God, asking "Why me?" We rail at the unfairness of being struck with this disease. We feel hurt, that it's something personally done to us. Also, spiritual doubt leads us to questions of purpose and meaning, such as "If this is all there is to my life, what is the point of it? What does my life really mean?" There are as many spiritual experiences as there are human beings, each of us is unique, and yet there are some universal themes to our spiritual lives and those are often brought to mind during times of crisis.

Now here is where the rubber meets the road: if you relate to many of the characteristics and difficulties described above, the question is:

<u>What Do You Do About It?</u>

Do you suffer in silence, waiting for the feelings to pass? Do you decide this is normal and goes with the territory of APS? Do you tell yourself you must be weak because lots of people have it worse than you, and they don't complain? Do you protect your loved ones from knowing how you feel because they already have so much to deal with? Do you wonder if you deserve this emotional pain, if you are being punished for something?

Or do you consider telling someone you trust about how you are feeling, maybe asking for their input or advice? Does it occur to you to seek help from your health care team? Do you give yourself permission to accept assistance with your mind and spirit as you have accepted medical help for your body?

<u>Remember: Resisting Help Causes Needless Suffering</u>

Here's the deal. You are made up of a body, a mind, and a spirit. When any one of these is in turmoil, it affects the others. You are a whole person and it's up to you to take care of your whole self. When you deny yourself care and healing of the mind, body, or spirit you are participating in your own suffering. And this brings us back to FDR's words of wisdom: "All we have to fear is fear itself." Once we recognize how we are held back by our own fear, we have the opportunity to move forward and reclaim our lives in body, mind and spirit! This is redefining self care.

Seek out some resources soon. Ask a friend, neighbor, family member, your nurse or doctor, your minister or priest for a referral to a good therapist. Talk with your nurse or doctor about the options for medicine to treat depression or anxiety, consider the benefits vs. side effects carefully. Check out a support group for coping, form one with other people diagnosed with APS by asking them to meet for coffee. It only takes three people to form a group! It's most important that you not isolate yourself. And finally, trust that you are adjusting and that coping becomes easier as you redefine your personal need for self care.

One Fine Day

Written by: Dana Stuart

On a Friday afternoon in June, I rushed home from work, packed a cooler, rounded up my girls and we hit the road, I-35 that is, which is the highway that took us from our home to LaCrosse, Wisconsin where the APS Foundation of America, Inc. (APSFA) home office is located. Having lost my glasses, I had to wear my prescription sunglasses for 7 hours in the dark. When we arrived at our hotel at 1:00 in the morning, we were extremely exhausted. But the long trip and exhaustion didn't ruin the excitement of finally getting to meet Tina, the APSFA President. As one of the founding members of the APSFA and a member of the steering committee, I have worked closely with Tina and the board of directors for quite some time. Throughout the last two years, Tina and I have spent many hours on the phone working and just having girl gab time. It was wonderful to finally meet my friend who has been there for me during the most difficult time in my life, when I lost my twins, and through all of the other day-to-day stressors. It felt like we had known each other for years. That alone was worth the trip.

The most important aspect of the trip, however, was the celebration of APS Awareness Month. In honor of this accomplishment, we donned our APSFA T-Shirts, armed ourselves with foundation literature and hit the pavement. Accompanied by my two adolescent daughters, we infiltrated the local hospitals in LaCrosse. We distributed literature and spoke to everyone we could about APS. We also provided bags full of baby gift items for the OB units and spent some time talking to the OB nursing staff, including the instructor of one of the prenatal classes who had more than 50 people attending her class that day.

Unfortunately, we didn't have a great reception. Most of the people we spoke to had no clue what APS was and they were somewhat hesitant to learn anything about it. But that didn't stop us. Regardless of the lack of knowledge or understanding, we continued on our journey to spread APS awareness and will continue to. It was also a great learning experience for my daughters who had many questions along the way and demonstrated the importance of speaking up and taking action. Hopefully, next year we will have better luck. In the meantime, we'll keep working until one fine day when APS screenings are part of routine checkups.

Choices You Must Make to Live Successfully with Chronic Illness

Written by: Lisa Copen

1. Recognize that the illness is chronic

You will swim through the phases of grief for the rest of your life, because with a chronic condition comes new limitations as the illness progresses. Don't be too hard on yourself; reach out to others, build up friendships with those that understand, pursue new hobbies that get your mind off of the illness, take a second look at your faith and how this effects it.

2. Be a good advocate for your health

You know your body better than anyone else and the likelihood is that you will get tons of well-meaning advice from both friends and strangers. Be discerning in what you choose to follow and what you choose to let go. Kindly thank those that offer their advice but don't make any promises or feel obligated to try anything they offer.

3. Do research on new medications and study possible alternative treatments carefully

Be wise in how much money you invest in alternative treatments; don't continue to dump money into alternative treatments when the practitioners continue to offer promises and testimonials. Recognize that alternative supplements are not regulated by the FDA and may not be as effective as they claim or even safe.

4. Choose your doctors carefully

Ask for referrals. Find a doctor who your personality clicks with. Don't be demanding or act like you know more than s/he does, even if you occasionally do. Build a team of doctors that is willing to work with you to give you the best quality of life.

5. Refuse to give into bitterness

It's easy to get caught up in the blues of "but they don't understand!" and "they are so lucky and they don't even appreciate it!" Defy the tendency to feel sorry for yourself and instead choose joy. One of the best books I've read on the this topic is Tim Hansel's "You Gotta Keep Dancin'."

6. Step outside yourself

Even if you aren't happy about the diagnosis, in time you will witness others going down this same path and you may have a desire to reach out. Follow that passion! Reaching out to another person who is dealing with similar circumstances can be healing for both of you and will give your illness purpose, even on the days with great physical pain.

7. Get a grip on guilt

It's natural, especially if you have a family, to feel intense feelings of guilt that you are bringing everyone down with you. Recognize that this illness is not a judgment or punishment—it simply is. You may not be able to choose to live without it but you can choose how to live with it. Your kids and spouse are watching to see how you will handle this. Make them proud.

8. Allow yourself to be vulnerable

On the flip side, you don't have to be a steel magnolia and always keep a stiff upper lip. Find a friend, a mentor, a buddy—someone who you can let down your frustrations, struggles, hopes and fears with. You'll find that illness may leave you with fewer friends than before but the quality of relationships may be much more precious.

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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.

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Have you seen our CafePress store lately?

We have hard at work creating some new, fresh designs for our CafePress store! We now have items available for the following syndromes or diseases which are related to APS: Vertigo, Sjögren's, Raynaud's, Stroke, TIA, Heart Attack, MS and Migraines. We have also added new designs to our Lupus, FVL and APS lines. Our CafePress items are high quality and the clothing comes in a variety of sizes from infant to many different adult sizes, including plus and maternity. Many items also come in a variety of colors. The APSFA gets to keep a small % of each sale from our store when you buy from it, so not only will you get a quality item, but you also make a donation to a worthy cause! Check out our store at the address below and be sure to check back often—we have more new designs in the works!

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