



# ANTIPHOSPHO...WHAT?

APS Foundation of America, Inc. Newsletter

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## Getting To Know Your Medical Advisors

Written by: Keith R McCrae, MD



Hi! I am a new member of the advisory board, and would just like to provide a bit of my background as an introduction.

I am currently a physician in the Hematology-Oncology Division at Case Western Reserve

University/University Hospitals of Cleveland, where I have been for the last 10 years. Prior to coming to Cleveland, I went to medical school and trained in internal medicine at Duke University, then entered a hematology-oncology fellowship at the University of Pennsylvania, subsequently joining the faculty there. After several years at Penn I joined the Sol Sherry Thrombosis Research Center at Temple University, where I remained for five years prior to relocating to my current position.

I have had an interest in antiphospholipid antibodies for approximately 20 years, since my fellowship. During that time, I worked under Dr Douglas Cines at Penn, who was an expert on endothelial cells. Endothelial cells are the cells that line all of our blood vessels, and play a critical role in maintaining blood fluidity. While at Penn, I became interested in studying the interactions of antiphospholipid antibodies with endothelial cells, and demonstrated that antibodies in patients with the APS were capable of binding to endothelial cells grown in vitro (in a dish) and causing them to become activated. When an endothelial cell becomes activated, it no longer is able to maintain blood fluidity and instead begins to express procoagulant functions—

i.e. it actually acts to promote blood clotting. Defining the mechanisms by which antiphospholipid antibodies cause this effect on endothelial cells has been my research interest ever since. Over the years we have found that these antibodies depend on the cofactor, beta 2-glycoprotein I ( $\beta_2$ GPI) to bind and disrupt endothelial cell function. We believe that this occurs through the ability of these antibodies to cluster endothelial cell-bound  $\beta_2$ GPI and cause signals to be transmitted to the inside of the cell, leading to its changed behavior.

We are also interested in defining markers of endothelial cell activation in patient blood. To address that issue, we are studying blood from patients with antiphospholipid antibodies, and measuring microparticle numbers. Microparticles are small pieces of cells that are released by the cells when they die are become activated, for example by antiphospholipid antibodies. We are actually measuring microparticles from a number of different cell types, including endothelial cells, platelets and monocytes. These studies are being performed in collaboration with a group of doctors at the Cleveland Clinic.

I have quite a few patients with antiphospholipid antibodies, some of whom are members of the APS foundation. As both a clinician and a laboratory scientist, I enjoy seeing patients with APS as well as performing research. If any patients in my area would like to see me for advice, a second opinion, or anything else, I would be happy to help.

I look forward to working with the APS foundation, and am thankful for the opportunity to join the advisory board.

## Are You Mapped?

Do you have a pin in our map?? If not, please add it. We are watching in amazement to see the clusters of APS people forming. Our Frappr map is located at: [www.frappr.com/apsfa](http://www.frappr.com/apsfa)

## Patient Stories & Articles Needed!

We are in need of patient stories to feature in our newsletters. Every APS patient has a story to tell and yours could be shared with the entire APS community.

We also need related articles such as book reviews, poems, recipes, interest articles, quotes, etc.

If you are interested in sending us your story, please write to [articles@apsfa.org](mailto: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



Fall will soon be upon us. Summer is certainly going by too fast. Way to fast to fast for me. I am not ready for summer to end, as here in Wisconsin, it has been just about a perfect summer.

June was APS awareness month and we'd like to say thank you to everyone that helped make this year's awareness month a success! And a special thanks to Jeff Cecil with JMC Creative for making this year's radio spots. Next year will be bigger and better and we aim to even more airwaves. We do still have raw PSAs that are available for year round use. If you are with a radio station or have a radio station that would be willing to run our PSA, please contact us at [apsfa@apsfa.org](mailto:apsfa@apsfa.org) for the raw file and we will send it directly to the radio station.

We did get quite a few press releases and Public Service Announcements (PSAs) about APS out. This included both paper media and YouTube. We have had some great feedback from these PSAs and hope to see more aired in the future. You can find all the PSAs located here: <http://www.youtube.com/user/APSFA>.

This year we did something a little different and focused on our social media such as Facebook and Twitter. We are very happy with the response we got and how many people our tweets and information helped. We had a list of prewritten tweets for people to use during the month of June. We will also be making a Tweet Sheet for year round use. Please watch the downloads section on the website for when it is released.

Unfortunately, with our main focus on social media, came a reduction in the donations we normally receive during June. We do realize that for a lot of our readers that money is tight right now. Here's our dilemma – we were invited to sponsor and attend the 13th International Congress on Antiphospholipid Antibodies in Galveston, TX however, the cost for an informational booth alone is \$4000. This does not include the cost to print our materials, travel, lodging, etc. We send what we can but at this time we are not able to sponsor as much as we want unless the donation situation changes dramatically between now and the time of the conference. If anyone has suggestions or can help, please feel free to contact us.

We are collecting articles for our newsletter. 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 not listed here and are not sure if it would be appropriate? Drop us an email at [articles@apsfa.org](mailto: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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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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## Use of Rituximab in the Antiphospholipid Syndrome

Written by: Robert A. S. Roubey, MD  
University of North Carolina at Chapel Hill

In recent years there has been a lot of interest in using rituximab for various autoimmune diseases, including the antiphospholipid syndrome (APS). In this brief article, I'll review basic information about this medication, its FDA-approved uses, off-label uses, risks and side effects, and the published experience of its use in APS.

### What is rituximab?

Rituximab (brand name, Rituxan) is a monoclonal antibody directed against a molecule called CD20, which is present on the surface of B cells (B lymphocytes), a type of white blood cell. Monoclonal antibodies are laboratory-produced molecules that are designed to bind to a specific target molecule (antigen). In a typical immune response to an antigen, the antibodies produced are polyclonal; in other words, the immune system makes antibodies with a wide range of different structures in their antigen-binding regions and other areas of the molecule, and that recognize multiple parts of the antigen. In contrast, monoclonal antibodies made in a laboratory, are identical molecules that bind to a single structure on the antigen. The monoclonal antibody that eventually became rituximab was initially a mouse antibody. Since humans would recognize a mouse antibody as foreign and react to it, to allow for its use in humans the antibody was carefully engineered to replace most of the mouse structures with comparable human structures. Rituximab is mostly, but not fully, humanized.

### What does rituximab do?

Rituximab binds to CD20-bearing B cells and causes the destruction and

elimination of these cells. It was initially developed as a treatment for B cell cancers, such as non-Hodgkins lymphomas in which CD20 is present on the tumor

**“Rituximab is generally useful in treating thrombocytopenia that does not respond to first-line medications...”**

cells. In this disease, rituximab binds to and causes the destruction of the tumor cells. Unrelated to cancer, B cells are an important part of the healthy immune system, particularly the part of the immune system that makes antibodies. The human body makes millions of different B cells, each of which is programmed to respond to a particular antigen. If a B cell encounters its antigen, it becomes activated, multiplies, and makes antibodies against that antigen. The stimulated B cells may go on to become “full-time” antibody-producing cells called plasma cells. B cells also play a role presenting antigens to other cells in the immune system. Basic research has found that B cells are important in the development of autoimmune diseases and the production of autoantibodies in these diseases. Depletion of B cells is, therefore, a potentially attractive approach to treating certain autoimmune diseases.

### What are the approved uses of rituximab?

Rituximab was approved for the treatment of B cell non-Hodgkins lymphoma in 1997. It was the first monoclonal antibody approved for the treatment of cancer in the United States. In 2006, rituximab was approved for the treatment of moderate to severe rheumatoid arthritis, based on several randomized clinical trials.

### Off-label uses of rituximab

Although drugs are approved by the FDA for specific uses, doctors sometimes use approved drugs for non-approved purposes. This is usually done when facing a severe, life-threatening disease that has not responded to standard medications and the remaining therapeutic options are very limited. In some cases, an off-label use may become the “standard of care,” that is, the generally accepted treatment by physicians and recognized (and paid for) by insurers. Because basic research suggests that B cell depletion may be of benefit in autoimmune diseases, rituximab is being tried and investigated in a wide variety of conditions including systemic lupus erythematosus, Sjogren's syndrome, autoimmune thrombocytopenia, multiple sclerosis, and some forms of vasculitis. A review of the use of rituximab in all of these diseases is beyond the scope of this article. Because of their relationship to APS, I'll comment briefly on the use of rituximab in autoimmune thrombocytopenia and in lupus. Autoimmune thrombocytopenia (also called idiopathic thrombocytopenia, immune thrombocytopenic purpura) is a disease in which autoantibodies destroy platelets, small cells in blood that control bleeding. Very low platelets counts can lead to bruising and severe bleeding. Standard, first-line, treatment of autoimmune thrombocytopenia is corticosteroids (prednisone) and/or intravenous immunoglobulin (IVIG). Rituximab is generally useful in treating thrombocytopenia that does not respond to first-line medications; many hematologists now consider rituximab to be “standard of care” for patients with

*(Continued on page 6)*



## Dusti's APS Story

Written by: Dusti

Hi, my name is Dusti, I am 26 years old and I was diagnosed with APS 3 years ago after I had my second miscarriage. My sister also has APS. She unfortunately found out she had APS after she was forced to give birth to her first child at 6 months in her pregnancy. Christopher was born April 10th and sadly passed on July 1st. When he was born his umbilical cord was the size of a pencil lead. This raised concern in her doctor, and she was then tested for APS. Since she had tested positive for APS when she became pregnant again, she was put on Heparin and now has a healthy 4 year old little girl named Michelle.



My husband and I had been trying to get pregnant for 2 and a half years when I had my first miscarriage. Since at the time I did not know I was pregnant, I did not know to tell them about my sister having APS. After that I was sent to the Jones Institute for Reproductive Medicine and a rheumatologist. As soon as I arrived to the Jones Institute they told me they wanted to do a hysteroscopy, cystectomy and check to make sure my tubes were clear. I saw them for a year with no luck and decided to stop seeing them.

Two and a half years later, I was pregnant again. This time I knew to tell the doctors about my sister having APS. I went to the same doctor she saw when she was pregnant with her daughter. I kept telling them to please test me for APS. I just wanted to be sure I didn't have to be on heparin. I even had my sister's medi-

cal records mailed to the doctor. They didn't think it was necessary to test me and at 8 weeks pregnant I started bleeding. A month later, after continuous bleeding, I went in for an ultrasound and they no longer could detect a heartbeat.

Again, I was sent to a fertility clinic. This time they sent me to the New Hope Center. They found out what was wrong. During my previous surgery at the Jones Institute they scraped my uterus, removing unnecessary debris. While this type of procedure is normal and most people do not have any problems afterward, I unfortunately was not as lucky as most. Instead of my uterus healing normally, it healed together causing the middle of the uterus to scar together. They also tested me for APS and came back with the results that it would be necessary for me to be on heparin during any pregnancy. But before I could try to get pregnant I would have to have another surgery to fix my uterus.

A year after the surgery and finding out that I do have APS, I found out I was pregnant again. This time when I called the doctor they put me on heparin right away. I am now 7 months pregnant with a girl. I have been on heparin from the beginning of this pregnancy. I have never made it this far in a pregnancy. I know that I have made it this far because the doctor finally listened and tested me for APS. I am on 8000 units of heparin twice a day and I will continue to take heparin until the end of the pregnancy. My sister was told that

APS only affects people while they are pregnant. I must disagree with the doctor who told her that. After I found out I was pregnant this time I started doing research on the few sites that talk about APS and have found that the many symptoms I had as a child, from severe stomach pains to aches in my arms, could be from having APS.

This website has given me a whole new look at APS. I know that I should not just forget about having APS after my pregnancy.

## No One Is Beat

Written by: Edgar Guest



No one is beat till he quits,  
 No one is through till he stops,  
 No matter how hard failure hits,  
 No matter how often he drops,  
 A fellow's not down till he lies  
 in the dust and refuses to rise.  
 Fate can slam him and bang him  
 round,  
 And batter his frame till he's sore,  
 But she never can say that he's  
 owned  
 While he bobs up serenely for more.  
 A fellow's not dead till he dies,  
 Nor beat till no longer he tries.

## New Oral Anti-coagulant to Replace Warfarin?

Written by: Jay S. Wirawan & So A. Yeung, Pharm D. Candidates  
University of Colorado at Denver, Denver School of Pharmacy  
Reviewed by: Al Lodwick, RPh, MA

With the advances in anti-coagulation therapy, we have seen many breakthroughs in recent years with injectable drugs. However, we only have one FDA approved oral anti-coagulant, warfarin, available for use in the United States. Elsewhere in the world, another oral anti-coagulant, Xarelto® (rivaroxaban) by Bayer™, has been approved for use in patients who are undergoing hip or knee replacement surgery in more than 30 countries. Despite its world-wide use, rivaroxaban is currently under review by the FDA before approval for use in the United States pending the need for more data. However, research that has already been done to date has shown promising benefits of rivaroxaban over Lovenox in preventing blood clots.<sup>1</sup>



In one study, rivaroxaban and Lovenox were compared for use in people who have had a total hip replacement surgery. Study subjects on Lovenox are four times more likely to develop clots compared to those who are on Rivaroxaban.<sup>2</sup> In a review article by Rosencher et al, an oral daily dose of Rivaroxaban was shown to be superior to Lovenox and side effects profiles were similar between the two groups.<sup>3</sup> A third study by Eriksson et al, shows that rivaroxaban has similar effectiveness and safety compared to Lovenox for clot prevention after total hip replacement with the convenience of once daily oral dosing and without the need for monitoring.<sup>4</sup>

Even though the lack of need for drug monitoring seems to be an advantage of rivaroxaban, some may question whether it may do more harm than good. One expert in the field of anti-coagulation, Al Lodwick, founder of Warfarin Institute of America sheds some light in this debate in our interview. When we asked him whether the lack of need for monitoring of a drug would be beneficial, he replies “it is both an advantage and disadvantage.” He goes on to say that it is an advantage because patients will not need for fre-

quent lab tests. However, it is a disadvantage because without drug monitoring, it would be difficult to know whether the drug is effective for the patient or if the drug is properly administered. A clotting event may be the only and final sign that it was not.

Another issue with regards to new drugs in the market is its cost compared to the available drugs on the market. Al Lodwick states that rivaroxaban currently costs about \$7 per tablet in Europe. For prevention of blood clot after total hip and knee replacement, rivaroxaban overall is less expensive than Lovenox. However, there are still no published studies regarding cost of rivaroxaban for long-term use.

With such promising results for use of rivaroxaban over Lovenox, some may wonder if it would be superior to other anticoagulants such as warfarin. Although current studies have only focused on effectiveness of rivaroxaban in total hip/knee replacements, we may see future research in other disease states such as APS. If approved, rivaroxaban may provide another option for oral anticoagulation therapy for people with APS. However, do not expect this to happen in the foreseeable future.

1 Nainggolan, L. Rivaroxaban Recommended for Approval by FDA Advisory Panel. Heartwire[Serial Online] 2009 [Cited 2009 July 1]: Available from: URL: <http://www.medscape.com/viewarticle/589941>

2 Kakkar AK, Brenner B, Dahl OE, et al. Extended duration rivaroxaban versus short-term enoxaparin for the prevention of venous thromboembolism after total hip arthroplasty: a double-blind, randomized controlled trial. Lancet [Serial Online] 2008 July [Cited 2009 July 1]: 372(9632):6-8. Available from: URL: [http://O-www.sciencedirect.com/library.uchsc.edu/science?\\_ob=ArticleURL& udi=B6T1B-4SV1JVY-1& user=418620& coverDate=07%2F11%2F2008& rdoc=1& fmt=& orig=search& sort=d& docanchor=& view=c& auct=C000019840& version=1& urlVersion=0& userid=418620& md5=47afafa0cd2e87508cc04b8362f37e50](http://O-www.sciencedirect.com/library.uchsc.edu/science?_ob=ArticleURL& udi=B6T1B-4SV1JVY-1& user=418620& coverDate=07%2F11%2F2008& rdoc=1& fmt=& orig=search& sort=d& docanchor=& view=c& auct=C000019840& version=1& urlVersion=0& userid=418620& md5=47afafa0cd2e87508cc04b8362f37e50)

3 Rosencher N, Arnaout L, Chabbouh T, Bellamy L. Rivaroxaban (Xarelto): efficacy and safety. Ann Fr Anesth Reanim [Serial Online] 2008 Dec [Cited 2009 July 1]: Suppl 3:S22-7. Available from: URL: [http://www.ncbi.nlm.nih.gov/pubmed/19185784?ordinalpos=1&itool=EntrezSystem2\\_PEntrez.Pubmed.Pubmed\\_ResultsPanel.Pubmed\\_DiscoveryPanel.Pubmed\\_Discovery\\_RA&linkpos=5&log\\$=relatedreviews&logdbfrom=pubmed](http://www.ncbi.nlm.nih.gov/pubmed/19185784?ordinalpos=1&itool=EntrezSystem2_PEntrez.Pubmed.Pubmed_ResultsPanel.Pubmed_DiscoveryPanel.Pubmed_Discovery_RA&linkpos=5&log$=relatedreviews&logdbfrom=pubmed)

4 Eriksson BI, Borris LC, Dahl OE, et al. A Once-Daily, Oral, Direct Factor Xa Inhibitor, Rivaroxaban (BAY 59-7939), for Thromboprophylaxis after Total Hip Replacement. Circulation [Serial Online] 2006 [Cited July 1, 2009]: 114:2374-2381. Available from: URL: <http://circ.ahajournals.org/cgi/content/full/114/22/2374>



(Continued from page 3)

refractory or recurrent disease. There has been considerable interest in using rituximab to treat refractory cases of lupus. It is estimated that as many as 10,000 lupus patients have received rituximab off-label. Case reports and case series have been very promising. Recently, however, preliminary reports of two major clinical trials of rituximab for lupus did not meet their primary clinical endpoints or outcome measures. Failure to meet the primary outcome measures in these studies is disappointing but may be related in part to certain aspects of the studies' designs. Data are still being analyzed from these studies.

#### **What are the side effects of rituximab?**

The most serious potential side effect of rituximab is a life-threatening viral infection of the brain disease called progressive multifocal leukoencephalopathy (PML). This disease is rare and the risk associated with rituximab is probably quite low. Another side effect is tumor lysis syndrome. This occurs when rituximab is given for cancers and large numbers of tumor cells are destroyed rapidly; it is probably not a concern when rituximab is given for rheumatoid arthritis and other autoimmune diseases. Other side effects include an increased risk of infection, infusion reactions, and severe skin rashes.

#### **Is rituximab useful in APS?**

We recently reviewed the medical literature and found reports of rituximab being used in 22 patients with APS. The patients ranged in age from 5 to 69, with an average age of 38. 15 patients were women and 7 were men. The clinical manifestations of APS in these cases varied widely; they included recurrent blood clots, critically low numbers of platelets counts,

various neurological problems, and the catastrophic APS. In general these problems had not responded to aggressive treatment with other medications. Overall, rituximab appeared to be helpful in 20 of the 22 patients, with partial or complete resolution of symptoms. Two patients did not have improvement, one of whom (with catastrophic APS) died. Information about the levels of antiphospholipid antibodies after treatment was provided in 13 cases; in 11 of these 13 patients antiphospholipid antibodies decreased or were no longer detectable after rituximab treatment.

Although these case reports are encouraging, they need to be interpreted with caution. First, the number of cases is small and experience treating larger numbers of patients may be quite different. Secondly, case reports lack controls. We know how a patient did after treatment but we cannot know how that patient or similar patients would have done without treatment or with alternative treatments. Thirdly, there is typical bias in the publication of case reports. Physicians treating patients with a new or unproven drug are much more likely to write up a case if the drug was helpful than if the drug was not helpful. Also, medical journals are more likely to publish papers with positive results. Thus, we don't know the complete picture. Rituximab has almost certainly been tried in more, perhaps many more, APS patients than just the 22 individuals whose cases have been published. We do not know the outcome of treatment in these unreported cases; it is possible that the drug was not helpful in many, or even most. To get a true understanding of whether rituximab is useful or not in APS, we need to know the results of treatment in all patients (reported and



unreported). These issues highlight some major reasons why clinical trials are much more useful and informative than case reports. In a well-designed clinical trial there are sufficient numbers of similar patients, there are controls (patients receiving a placebo or other therapy), and outcomes are reported for all patients and controls. To date, there have not been any controlled clinical trials of rituximab in APS.

#### **Conclusions**

Rituximab is a therapeutic monoclonal antibody that depletes B cells. It has been in clinical use for over a decade and is approved for certain B cell malignancies and for rheumatoid arthritis. Rituximab is also being widely used for severe autoimmune thrombocytopenia that does not respond to corticosteroids and IVIG. Although rituximab is not approved for this condition, it has become the "standard of care." In certain situations, the off-label use of rituximab for various autoimmune diseases, including APS, is considered by physicians with expertise in treating these conditions. In general, rituximab is considered in cases of severe or life-threatening disease that have not responded to standard treatments. There are encouraging data from case reports that rituximab may be helpful in APS. These reports need to be interpreted cautiously, however, for the reasons noted above. Autoimmune thrombocytopenia in the setting of APS is typically mild and, if it requires treatment, usually responds to low or moderate doses of prednisone. In the rare cases when thrombocytopenia in APS is severe and does not respond to prednisone and IVIG, rituximab should be considered. Use of rituximab for other manifestations of APS is not well-established.

*Disclosure: Dr. Roubey has no affiliation with the pharmaceutical companies that manufacture or market rituximab and has not participated in clinical trials of rituximab.*



# Stroke: What You Need To Know for Better Health

Submitted by: Tina Pohlman

Each year, more than half a million Americans, suffer from strokes. A stroke, or “brain attack,” occurs when the blood supply is cut off from part of the brain. When this happens, the blood-deprived brain loses its supply of oxygen and nutrients. When the brain is deprived of blood for even a few minutes it begins to die.<sup>1</sup>

There are two types of stroke – ischemic and hemorrhagic. In ischemic strokes, brain arteries become blocked and prevent blood from nourishing the brain. In hemorrhagic strokes, brain arteries rupture from damage caused by high blood pressure and other risk factors or an aneurysm (an abnormal outpouching of a blood vessel) and cause blood to flood the brain, creating pressure that leads to brain-cell death.

## Warning Signs of Stroke

Depending on the function of the part of the brain affected, the person suffering the stroke suddenly may become paralyzed, blind or unable to speak.



If you experience any of the major stroke warning signs listed below, call 911. It is important to get to a hospital immediately. The chances for survival and recovery improve when treatment begins within the first few hours of stroke warning signs.

- Sudden loss of speech
- Slurred speech
- Sudden loss of vision
- Blurry or double vision

- Sudden paralysis
- Sudden weakness
- Sudden dizziness

Sudden, severe headache, often accompanied by neck stiffness and vomiting

## Risk Factors for Stroke

- High blood pressure
- High cholesterol
- Heart disease
- Being overweight
- Heavy drinking
- Smoking
- Being male (Men are more likely to have strokes than women.)
- Being African American (African Americans have a higher rate of stroke than other races.)
- Being older than 55
- Being diabetic
- Having a family history of stroke

## Do You Want to Reduce Your Risk?

- Control your blood pressure.
- Find out you have heart disease, especially an irregular heartbeat known as atrial fibrillation (AF)
- Don't smoke
- Find out if you have a diseased carotid artery (arteries that provide blood flow to the brain)
- Lower your cholesterol
- Limit your alcohol intake
- Control your weight
- If you have diabetes, manage the disease

To read more about strokes go to:

APS Foundation of America, Inc: <http://www.apsfa.org/stroke.htm>

National Institute of Neurological Disorders and Stroke: <http://www.ninds.nih.gov/disorders/stroke/stroke.htm>

American Stroke Association: A Division of American Heart Association: <http://www.strokeassociation.org/>

## References:

<sup>1</sup> *Health Advantage, Spring 2008, page 10, ClevelandClinic.org/HA*

## Ward 14 (October)

Written by: Pattiyan

From my bed I watch the fluttering leaves  
 making silhouettes of birds against a far window's light  
 Balloons make their own dance in the window's breeze  
 A birthday balloon makes tours around it's base  
 A smiling 'sun' clings to the ceiling free of it's reins.....



The leaves are doing a different dance tonight  
 and the 'birds' have gone  
 Firecrackers have taken their place



## 20 Things NOT To Say & TO Say To Someone With a Chronic Illness

Written by: Lisa Copen

These two lists are some great examples of what TO say and what NOT to say to a loved one who has a chronic illness, especially to those who have an invisible illness.

### 20 Things NOT To Say To Someone With a Chronic Illness

### 20 Things TO Say To Someone With a Chronic Illness

You look so good today!

You just need to get out of the house more.

If you stop thinking about it, the pain will go away.

You should just pray harder.

You must not want to get better if you won't try this.

When I was your age I didn't have the luxury of being sick.

You're sick again??

I wish I could just sit/lay around all day.

No pain, no gain!

I'd be sick too if I saw doctors as much as you do.

I have this juice that is working wonders...

You must still have sin in your life.

If you got a job you'd have something else to think about.

Your illness is caused by stress.



You can't be in that much pain. Maybe you just want attention.

What have you done to make God so mad at you?

There are easier ways to get attention.

It's not good for your kids to always hear you whining.

When are you going to get rid of that cane/walker?

I'm so glad to see you out and about feeling all better.

I don't know what to say, but I care about you.

I'm going to the grocery, what can I get you?

Do you just need to vent? I'm all ears!

If you need a good cry, I've got plenty of tissues and a shoulder.

I really admire how you are handling this. I know it's difficult.

I'm bringing dinner over (any)day. Do you want lasagna or chicken?

Can I borrow take your kids for a play date? My kids are bored.

I can't sit still. Got any laundry I can fold?

What can I pray for you about that no one else is praying for?

Can I bring a few friends over to clean your house real quick for you?

I don't have any idea how you are feeling, but I will always listen.

I saw these flowers and thought they'd cheer you today.

How can our church encourage those with chronic illness?

Tell me what it is really like to be you for a day.

I made too much dinner for our family. Can I bring you some?

You are amazing. How has your illness given you appreciation for life?

Do you want me to come over while you wait for test results?

You listen to me better than any other friend. Thanks.

I have (any)day free if you need me to run some errands or take you somewhere.

Tell me about this God who gets you thru one more day?



These lists were written and tweeted by Lisa Copen and then they were retweeted by many others on Twitter. Lisa is from the National Invisible Chronic Illness Awareness Week site and we have featured some of her writings in past newsletters. Lisa has joined us on Twitter to help spread awareness for APS and we plan on being a guest blogger on her blog in the future.

You can follow Lisa on twitter at <http://twitter.com/invisibleillwk> or visit her website at <http://invisibleillnessweek.com/>.



## Marv's APS Story

Written by: Marvin Nelson

I was born in 1934 in Michigan and to save you the calculation, I will tell you that makes me 75 and I will be 76 on Jan, 22, 2010. I now live near Raleigh, North Carolina in the USA.

In late 1995 I had a heart problem called A-flutter. My heart was beating about 2 times as fast as it should have been. It probably had been out of time for several months but caused quite a stir in the doctor's office when the nurse took my pulse. My pulse was over 150. Very quickly I was on a gurney getting IVs and aspirin, with paramedics all over the place, then to the ER and then to intensive care for nine days. They tried some meds but finally shocked me with the paddles to get

me back into a sinus rhythm. The heart doctor put me on several medications, one of which was Quintidine and I have since seen that this drug can be a trigger for APS.

In March of 1996 I had a massive DVT in my left leg. This was treated with Coumadin but I was taken off the Coumadin "to see what would happen" LOL. A couple of months later I had a second DVT in the same leg. Later I had two embolisms in the lungs about four months apart and later



numerous TIAs. Two of the TIAs crippled my right side and I could not make any intelligent speech. They lasted about four hours each. In the process I saw 12 doctors including my primary care doctor who was very supportive all of the time. The 13th doctor was Dr. Ortel from Duke University who diagnosed me based on symptoms and elevated IgM and lupus anticoagulant.

I have been on Coumadin since and have a lot of problems but none that seem to be related to APS. Physically I feel good and seem to have about the same mental capacity as I had when I was younger. I take about 80 mg. of Coumadin a week.

## Social Networking for APSFA

Written by: Heidi Ponagai

Just about everyday I overhear someone asking someone else, "Are you on Facebook?" or "Do you Twitter?" or "Do you have a MySpace page?" It seems everyone's been bit by the social networking bug.

Many businesses and non-profits are also using these types of sites to provide information, hold special contests, and just connect with the consumers. Even news stations and large medical websites such as WebMD are tweeting away about breaking news and the latest in migraine research.



By joining these social networking sites not only can you keep in touch with long lost friends from school or past jobs, but you can also get reminders that your favorite show is on TV, get a preview of next week's episode, get weather & traffic updates, or find out that Tyra Banks really wants to get fake nails but she's afraid of ripping them off because that

hurts worse than a papercut!

In June, the APSFA decided to take our APS Awareness campaign to the internet.

On Facebook, we made an application that allowed people to give APS Awareness "gifts" to their friends and asked them to pass them around. We also posted graphics from our Cafepress items and asked others to share them on their Facebook wall. We made APS Awareness flair. We posted videos & links to our newsletters and brochures. We posted and shared our PSAs and press releases.

On Twitter we tweeted and retweeted APS Awareness phrases. We added "twibbons" to our profile pictures and joined "twibes". We contacted and were contacted by other people who have APS and never knew there was an Foundation for APS in America. We fit all the awareness we could into the 140 character limit there is on Twitter.

On MySpace we posted our videos, many blogs and left comments on our friends'

pages promoting APS Awareness.

We were busy hitting the keyboard instead of hitting the streets this year! And I do believe we did so with great success! And we're still at it!

If you'd like to becoming involved with our social networking campaign, you'll find us at the following links.

Facebook:

<http://www.facebook.com/home.php?ref=home#/pages/APS-Foundation-of-America-Inc/41248276562?ref=sgm>

Twitter:

<http://twitter.com/apsfa>

Add a Twibbon on Twitter:

<http://twibbon.com/join/APS-Awareness-APSFAorg>

MySpace:

<http://www.myspace.com/antiphospholipidantibody>

YouTube Channel:

<http://www.youtube.com/user/APSFA>

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Online Support: [www.apsforum.com](http://www.apsforum.com)

FIRST  
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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.



Sponsored by: **OPEN**

## Do you send fresh flowers to family, friends, or other loved ones?

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

<http://apsfa.flowerpetal.com>

When you order flowers at <http://apsfa.flowerpetal.com>, 12% of each purchase goes to the APS Foundation of America, Inc.



There are no additional fees for delivery – including same day delivery. This means you can save up to \$12.95 compared to other on-line florists. Every purchase puts a smile on many faces – including yours!

We have many autumn inspired baskets and bouquets that are now available, as well as fresh flowers for every occasion! So, check out our site and support the APSFA at the same time.

Tell everyone about [apsfa.flowerpetal.com](http://apsfa.flowerpetal.com) and help us make a difference.

