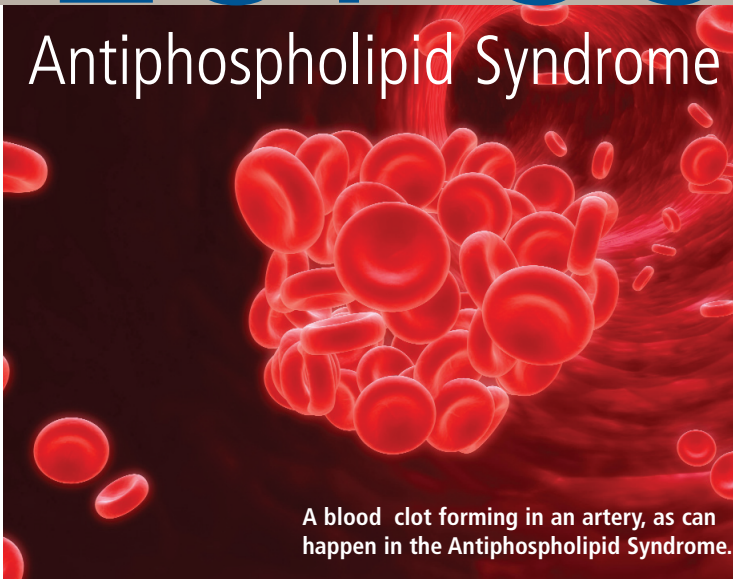




LUPUS NEWS

Antiphospholipid Syndrome



A blood clot forming in an artery, as can happen in the Antiphospholipid Syndrome.

Courtesy of Can Stock Photo Inc.

The Antiphospholipid syndrome is a condition in which individuals are predisposed to form blood clots in their arteries or veins or may have miscarriages or other pregnancy complications. In order to make the diagnosis of this disorder, an individual must have a positive blood test for an antiphospholipid antibody, and also have one of the clinical findings described above. The disorder can exist by itself or in conjunction with systemic lupus erythematosus.

There are several types of antiphospholipid antibodies. The first type of antibody that can be found in individuals with the antiphospholipid syndrome is an anticardiolipin antibody. A level of 40 units or higher of the IgM and/or IgG anticardiolipin antibody is considered to be significantly positive. While other subtypes (IgA and IgD) have been reported, they can not be used

to make this diagnosis. The second type of testing done is called a lupus anticoagulant. The test is reported as being either positive or negative. It is important to be tested for both the IgM and IgG anticardiolipin antibody and the lupus anticoagulant when being evaluated for this disorder because sometimes only one or the other of these tests will be positive. If these tests are both negative, and the antiphospholipid syndrome is still suspected, antibodies to beta2 glycoprotein I can be tested. Just as for the anticardiolipin assay, a level of 40 or higher of the IgM and IgG is considered to be significantly positive. In years past, it was observed that some patients who had a false positive test for syphilis but did not have syphilis, had antiphospholipid antibodies. As the testing for syphilis has become more specific these so called "false positives" are rarely seen. However, a history of having had a false positive test for syphilis in the right clinical setting should make one suspect the antiphospholipid syndrome.

The presence of these antibodies by themselves does not confirm the diagnosis of this syndrome. These antibody tests need to be positive on two separate occasions three months apart and the individual must also have had a blood clot or pregnancy complication. If the person who has these antibodies has had a venous clot (e.g. deep vein thrombosis, pulmonary embolism) or arterial clot (e.g. clot in an artery, heart attack, and/or stroke) or obstetrical complication (three or more first trimester miscarriages or a stillbirth) they are considered as having the antiphospholipid syndrome.

Individuals with positive antiphospholipid antibody tests who have had a blood clot in their veins or arteries should be treated with lifelong anti-coagulation. Anticoagulation is most commonly

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Tips of the season



1. Regular exposure to sunlight is important in maintaining normal vitamin D levels. Lupus patients may have low vitamin D levels because they are advised to avoid the sun. It is generally recommended that lupus patients take between 800 IU to 1000 IU of vitamin D daily. Be sure to speak with your doctor about vitamin D supplements.

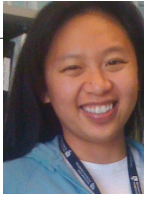
2. Taking corticosteroids on a daily basis like prednisone or Medrol can increase the risk of bone thinning (osteopenia and osteoporosis) and fractures. Regular weight bearing exercise like brisk walking helps to maintain bone health.

INSIDE

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Jade Cumberbatch

If you're a lupus patient, you already know that you only have a narrow selection of medications to choose from to treat your illness. Unfortunately, it has been many years since a new drug designed specifically to treat systemic lupus erythematosus has hit the market.



The BWH Lupus Center is trying to change that, and Jade Cumberbatch is playing an integral role in the process. Jade is a clinical trials coordinator, helping patients sign up for and take part in trials for new medications to treat lupus, as well as rheumatoid arthritis.

Though a big part of Jade's work is documentation—making sure all the i's are dotted and t's are crossed in the paperwork for these important studies—she also helps evaluate patients who express interest in taking part in the trials. "I screen patients for whether they would be a good fit," Jade says. She also oversees follow-up visits for patients in trials, making sure things are proceeding smoothly.

There are several trials going on right now that are recruiting for interested patients, she says. One is for a medication that might help prevent lupus-related flares, another will test the immune effects of Vitamin D in patients with lupus, and a third is for patients with lupus nephritis.

Jade stresses that patients who are interested in participating are not under any obligation. "I tell patients it's completely up to them to participate, that they should talk to their family and doctor and feel comfortable." The process can be extremely rewarding, she adds. "You're helping the research, and helping to determine how to treat lupus effectively."

Lupus Center to Publish Patient Cookbook



Do you have a favorite family recipe? Is your dish always the highlight of every party? Are you a talented cook wanting to share your cooking expertise with others?

If you answered yes, we'd like to hear from you!

The Lupus Center at BWH is collecting recipes to publish a special cookbook with recipes from our lupus patients. Proceeds from the "Lupus Cookbook" will be used to develop resources for lupus patients and their families. These activities include a mentoring program, patient education series featuring lupus experts, and an expanded website with important and highly topical information.

If you are interested in learning more about the Lupus Cookbook or want to send in your recipe, please contact Dawn Peters at dawnmpeters@comcast.net.

Tricia Brown

The next time you see your rheumatologist at Brigham and Women's Hospital (BWH), you may get the opportunity to meet Tricia Brown, a medical assistant in the Lupus Center. Since training at the Bryman Institute, now known as the Everest Institute, Tricia has been working at BWH for the past three years. "I love the staff and interacting with patients here," she says. "We have excellent doctors, and the patients know there is hope for a higher quality of life."



Tricia enjoys assisting Dr. Elena Massarotti and the other Lupus Center physicians with their procedures, which includes assessing synovial fluid to determine how much inflammation a patient is experiencing, and cleaning and stocking exam rooms in the clinic. "Dr. Massarotti is a lot of fun and easy to talk to," says Tricia of the rheumatologist who came to BWH shortly before Tricia. "She makes it a nice environment to work in."

As a medical assistant, Tricia might take your blood pressure, pulse, and other vital signs. She will ask you about any recent changes in your health and symptoms. Always a smile on her face, Tricia's key advice to patients is not to give up, to keep on fighting to control the illness and its effects.

The best part of her job, says Tricia, is seeing patients who experience dramatic improvements in their health after coming to the Lupus Center. "Sometimes I will see a patient two months later, and I don't even recognize him or her as the same person. I just saw a patient who was in a wheelchair a few months ago, and now she's up and walking around. It's a great feeling."

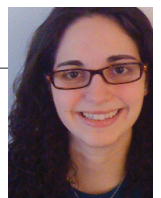
Nick Nassikas

A recent graduate of Colby College, Nick is a research assistant in the Division of Rheumatology. He is involved with projects working on expanding a Lupus Center SLE Registry and Biobank. Research assistant by day, student by night, Nick is taking pre-med classes with the goal of going to med school in the next couple years.



Candace Feldman, MD, MPH

A 2nd year BWH medical resident, has received the Martin P. Solomon Primary Care Scholarship Award from the BWH Department of Medicine to support her proposed project, "Access through Education: Building a Relationship with Medically Underserved Women with Lupus to Improve Health Literacy and Reduce Disparities." She is organizing a series of seminars and group discussion forums on lupus and health care access to take place in Roxbury, Dorchester and Mattapan.



Acorn Gallery and Cross Country Bike Ride for Lupus Donate \$12,500 to BWH Lupus Center

When Deborah Highberger and her husband started the Acorn Art School and Gallery, they had originally intended to work with special needs students. However, acknowledging the benefits of art for everyone, they expanded the school, located in Marblehead, Massachusetts, to include all types of students. As one of the young teachers at the Acorn Gallery during the summer, Jean-Marc



Jean-Marc Dykes and Deborah Highberger present a check for \$12,500 to Lupus Center co-directors, Drs. Karen Costenbader and Bonnie Bermas, on the left.

Dykes, a student at the University of British Columbia, developed a strong friendship with Mrs. Highberger. Before Mr. Dykes met Mrs. Highberger, he had never heard of lupus. That changed when Mrs. Highberger was diagnosed with lupus over four years ago.

Mr. Dykes once mentioned to Mrs. Highberger his dream of bicycling across the country. For

Mr. Dykes, the idea seemed more fantastic than realistic, but Mrs. Highberger turned to Mr. Dykes and simply replied, "Do it." An athletic woman, Mrs. Highberger also shared a passion for cycling. However, health problems that led to her diagnosis of lupus made it impossible for her to bike anymore and caused daily pain and limited function. After Mrs. Highberger found the Brigham and Women's Lupus Center, she received a personalized treatment plan and "began to gain her old self back," Mr. Dykes said.

In honor of his art teacher and mentor, Mr. Dykes approached Mrs. Highberger with the idea of a cross-country bike ride to raise money for the Brigham and Women's Hospital Lupus Center. Cycling 4,000 miles from Vancouver, Canada to Marblehead, Massachusetts, Mr. Dykes' "Cross Country for a Cure" bike ride cumulated in the JM Lupus Ride for a Cure fundraiser in Marblehead in February 2009. Organized by the Highbergers, Mr. Dykes, and their friends, and held at the Landing Restaurant, the evening fundraiser was attended by almost 200 people. Fundraising events included a fashion show featuring a local dressmaker, an art auction, a walk-through of the art school, and a talk on lupus by Dr. Peter Schur of the Lupus Center. A total of \$12,500 from the fundraiser were being donated to the Lupus Center. The Lupus Center greatly appreciated the effort and energy Mr. and Mrs. Highberger and Mr. Dykes put into the fundraising event. The perseverance that Mrs. Highberger has shown in fighting this disease, as well as the fortitude and motivation that compelled Mr. Dykes to ride across the country are truly inspiring.

BWH Lupus Center Events

Karen Costenbader, MD, MPH, was selected to receive the first annual Mary Betty Stevens Young Investigator Award for her research from the Lupus Foundation of America. Dr. Costenbader received the award in October at the Lupus Foundation reception in Philadelphia, Pennsylvania and gave a short acceptance speech in which she recognized and thanked the patients, physicians and colleagues of the BWH Lupus Center. Dr. Costenbader was also selected this year to serve on the Lupus Foundation of America's Medical and Scientific Advisory Board.

Bonnie Bermas, MD, gave two presentations titled, "Pregnancy and Rheumatic Diseases" and "Medication Use during Pregnancy," at the American College of Rheumatology Clinical Conference in Snowmass, Colorado, January 2010.

Elena Massarotti, MD, ran two "Meet-the-Professor" sessions, both of which were titled "Difficult Lupus" at the American College of Rheumatology Annual Scientific Meeting in Philadelphia in October 2009. In the same month, Dr. Massarotti was also a panelist in a clinical trials workshop held by the Alliance for Lupus Research in New York City.

ONGOING BWH LUPUS CENTER RESEARCH STUDIES

Systemic Lupus Erythematosus Biobank

This biobank is collecting blood samples for future studies. The biobank will look at how and why lupus occurs in lupus patients. The biobank is seeking participants with lupus. The participants must be older than 18 and seen by a doctor in the BWH Arthritis Center. Participants will be asked to complete a questionnaire and give a blood sample. For more information, contact Nick at 617-732-6676 or email nassikas@partners.org (IRB #: 2008-P-000130)

Vitamin D3 in Lupus

We are studying the possible benefits of vitamin D for lupus. To be eligible for this study, you must be at least 18 years of age or older and have a diagnosis of lupus. For more information, contact Jade at 617-732-5354 or e-mail at nhcumberbatch@partners.org (IRB #: 2008-P-002167)

Abatacept and Cyclophosphamide Combination Therapy or Lupus Nephritis (ACCESS)

Looking for subjects 16 or older who have SLE with active nephritis. The purpose of this study is to find out if abatacept, when used with cyclophosphamide, corticosteroids and azathioprine is safe and more effective in people when used in combination in patients with lupus nephritis. The study drug, abatacept, is not approved by the U.S. Food and Drug Administration (FDA) for the treatment of SLE but the FDA has approved abatacept for the treatment of rheumatoid arthritis. For more information, contact Jade at 617-732-5354 or e-mail at nhcumberbatch@partners.org (IRB #: 2008-P-002221)

LUPUS NEWS

Lupus Foundation of New England

The Lupus Foundation of New England is an organization that helps people and families affected by lupus. It provides resources for education and support. It also helps to fund lupus research with other lupus organizations.

Calendar of upcoming events sponsored by the Lupus Foundation of New England (www.lupusne.org)

Monday, April 19, 2010
114th Boston Marathon

Saturday, April 24, 2010
36th Annual Meeting and Symposium
Marriott Boston Newton, Newton, MA

Saturday and Sunday, June 12 and 13
7NBC CW56 Partners HealthCare Health & Fitness Expo
Hynes Convention Center, Boston, MA

Thursday, June 24, 2010
Commitment to a Cure Cocktail Party
Larz Anderson Auto Museum, Brookline, MA

Sunday, September 12, 2010
18th Annual Lupus Walk on the Charles
Richard T. Artesani Park, Brighton, MA

Antiphospholipid...continued from page 1

achieved with oral warfarin (Coumadin) and less commonly injections of heparin. Women who have had miscarriages or problems with past pregnancies and would like to attempt pregnancy should be treated with heparin (plus low dose aspirin) during a pregnancy. People who have these antibodies but who have never had a blood clot or pregnancy problem do not need to be treated. They may be at increased risk of future clotting or pregnancy problems. The best way to treat or follow them is not yet known. Some doctors prescribe daily low dose aspirin for these people.

There are other clinical findings seen in this disorder. Low platelets, kidney disease and a skin rash called livedo reticularis that looks like a lacy pattern of veins have also been observed. These clinical findings do not require treatment with anticoagulation unless the individual has also had a blood clot.

Although this syndrome occurs with higher frequency in individuals with systemic lupus erythematosus, it does not occur in all people with lupus and can occur in people without lupus at all.

If you have any of the clinical features discussed above you should discuss testing for this disorder with your rheumatologist.

If you are interested in learning more about the lupus center or supporting our research and educational programs please call Erica Dumas (617) 525-8589 or visit our website www.brighamandwomens.org/rheumatology/lupus/

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