Tips and information from the Lupus Center at Brigham and Women's Hospital

LUPUS NEWS

BRIGHAM AND WOMEN'S HOSPITAL

Volume 1 / No. 2

OSTEOPOROSIS

Successfully managing your lupus means being aware of all the possible consequences of the disease—one of which is osteoporosis.

Osteoporosis, a common condition that causes loss and weakening of bone, can go unnoticed and lead to fractures. These bones fractures can be very painful, leaving people with limited movement. However, osteoporosis can be prevented and treated. The disease can affect anyone, but most people with osteoporosis are women.

Women with systemic lupus erythematosus (SLE) are more likely to have osteoporosis than women without lupus. This is because there is a direct relationship between lupus and bone loss, sometimes due to the frequent use of steroids that treat lupus. An additional reason is that lupus patients often exercise less because of pain and tiredness. In addition to those factors, lupus can cause osteoporosis on its own.

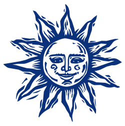
Osteoporosis prevention

Osteoporosis can be prevented. It is important that people who could develop osteoporosis get a bone mineral density (BMD) test, which can help identify osteoporosis in the body before it causes fractures. A BMD should be considered for people who take steroids for lupus, as well as for women who no longer menstruate.

Osteoporosis treatment

While osteoporosis cannot be cured, it can be treated. If a person suffers from osteoporosis, there are several ways to treat the condition:

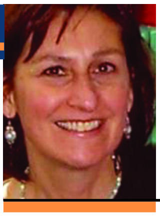
Vitamin D and calcium: It is very important that people get both vitamins as they help create healthy bones. Vitamin D can be gotten from exposure to sunlight, but since people with lupus can flare from sunlight, supplemental Vitamin D can be a great option. Supplemental options, containing both vitamins, include dairy products, dark greens, foods and drinks with vitamins, and supplements.



Exercise: Bone gets stronger with exercise. For people with osteoporosis, they can try to walk, run, dance, or lift weights. People with lupus may find exercise hard, but regular exercise can help strengthen bones and ease these symptoms.

Medication: Medications can be used to treat or prevent osteoporosis in postmenopausal women. Some lupus patients get osteoporosis from the use of steroids like glucocorticoids, but alendronate and risedronate may be used to treat it.

Women with systemic lupus erythematosus (SLE) are more likely to have osteoporosis than women without lupus.



The nurse will see you now

Lupus Center profile: Nurse Frances Griffin

Dealing with a chronic disease like lupus can be frustrating. Because the expression of lupus varies from person to person, patients may feel isolated and experience distinct periods of uncertainty. "That's why it's so important for patients to stay engaged with their doctors and come in regularly for check-ups to make sure their lupus is under control," says Frances Griffin, RN, BSN. A nurse in the BWH Lupus Center, Griffin has 33 years of experience, most of it spent caring for patients with arthritis and autoimmune diseases.

The Lupus Center is a key factor to maintaining that engagement, offering patients the opportunity to visit their doctors, and to take advantage of the knowledge of the nurses to talk over all questions, big and small. "We are available for them," says Griffin. "We can help with medication information, pain management, energy conservation tips, and coping strategies."

For many patients, fatigue is their biggest concern—and this fatigue might not be well understood by others, because lupus patients don't appear outwardly ill. Sometimes family and friends can benefit from counseling, which the Center can facilitate. "Most people realize that they can handle lupus if they have good support from family or friends," Griffin explains.

"The most significant way of contributing to your health is choosing how you think about yourself and your ability to handle situations as they come up," says Griffin.

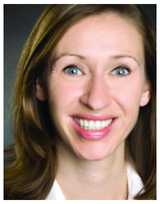
While a positive outlook and confidence is helpful, patients should use the Lupus Center whenever they need it. "Patients should know they have somebody in their corner, and that they can just stop by, express their concerns, and be heard and helped," Griffin says.

Saving your skin–Dr. Ruth Ann Vleugels

Having skin problems associated with lupus can greatly detract from your quality of life. Luckily for patients at BWH's Lupus Center, Ruth Ann Vleugels, MD, sees lupus patients specifically for their skin disease. Dr. Vleugels has the unique distinction of being a dermatologist with specialized medical training in complicated skin disorders, coupled with a passion for fighting autoimmune diseases, including lupus.

Many patients whose lupus is under good control on medications can still have persistent problems with their skin, making skin lupus challenging to treat, she admits. However, cutaneous lupus, or skin lupus, is one of the conditions Dr. Vleugels sees most frequently, making her well-prepared to treat patients with this challenging problem.

"Patients with lupus are often extremely sensitive to the sun, which makes practicing excellent sun protection essential as an initial step in improving their skin disease," she says. This includes not just wearing the appropriate sunscreen, but also wide-brimmed hats and sun-protective clothing. She can even recommend brands of makeup that work better for patients with lupus, or help curb hair loss, an unfortunate side effect that can accompany lupus.



Ruth Ann Vleugels, MD

There are medications that can help skin conditions associated with lupus—some are the traditional immunosuppressive drugs, while others are topical medicines and newer drugs called biologics. The key for patients is to take advantage of the knowledge of Dr. Vleugels and other clinicians available in the Lupus Center dedicated to helping patients with the manifestations of lupus.

"Skin problems are extremely common in lupus and can definitely affect patients' quality of life," says Dr. Vleugels. "Many patients can benefit from seeing both a rheumatologist and a dermatologist."

> *"Patients with lupus are often extremely sensitive to the sun, which makes practicing excellent sun protection essential as an initial step in improving their skin disease."*
>
> – Dr. Ruth Ann Vleugels

Researching lupus and kidney failure

Karen Costenbader, MD, MPH, co-director of the BWH Lupus Center, presented the results of her research examining rates of kidney failure in lupus patients at the American College of Rheumatology Annual Scientific Meeting in San Francisco in October 2008. She and her collaborators used information from the U.S. Renal Datasystem to study kidney failure among patients with lupus in the U.S. from 1995 to 2004.

A total of 10,035 cases of lupus caused end-stage kidney disease required dialysis or kidney transplantation during this period. The researchers found that the number of new cases per year grew 30%. Most cases (82%) occurred in women, growing 32% per year. Lupus kidney disease was most commonly found in African-American women, striking 4 in 100,000 African-American women compared to 100 in 100,000 Caucasian women and 50 in 100,000 African-American men.

This is the first study to show that the rate of end-stage kidney disease due to lupus is now higher in African-Americans than Caucasians. Overall, the fraction of new cases per year of lupus-related kidney disease in African-Americans increased from 45% to 49%, while the fraction in Caucasians dropped from 47% to 42%.

"Our findings suggest that possibly minority racial and ethnic groups in the U.S. are not receiving adequate healthcare for lupus and lupus nephritis, and/or they are not responding to treatment in the same way as Caucasians," said Dr. Costenbader. One issue may be medication compliance—but that may only be one factor of many.

Lupus Center fundraiser

Dr. Kichul Shin and Dr. Peter Schur attended the first fundraising event sponsored by Debra and Jack Highberger in Marblehead, Mass., on February 17. The event was initiated by the Highbergers to help raise money for lupus research in the BWH Lupus Center in response to the excellent care one of their family members received there.

The evening fundraiser, held at The Landing Restaurant, was attended by almost 200 people. Fundraising events included a fashion show of a local dressmaker with art students modeling, a raffle, a walk-through of the art school, and a talk on lupus by Dr. Schur. We thank the Highbergers for initiating this event, and for doing such a superb job of hosting it.

The BWH Lupus Center appreciates donations to help support its educational and research efforts.

ONGOING BWH LUPUS CENTER RESEARCH STUDIES

Systemic Lupus Erythematosus (SLE) Biobank:

The SLE Biobank is seeking participants with lupus, collecting blood samples for future studies to determine how and why lupus occurs. Participants must be older than 18 and have been seen by a doctor in the BWH Arthritis Center. You will be asked to complete a questionnaire and give a blood sample. For more information about this research study, please contact: Dr. Karen Costenbader (kcostenbader@partners.org) at (617) 732-5158,

IRB #: 2008-P-000130.

Vitamin D for 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 nhwilliams@partners.org

IRB #: 2008-P-002167.

APRIL

A new investigational medication for lupus flares. Dr. Elena Massarotti is the Principal Investigator at the Lupus Center at Brigham and Women's Hospital. Study Sponsor is EMD Serono. For more information call: 617 732-5354 or email: nhcumberbatch@partners.org

IRB #: 2008-P-000145.

Visiting lecturer

In September 2008, the Lupus Center and Harvard University hosted Dr. Susan Manzi, associate professor of Medicine at the University of Pittsburgh School of Medicine, for a two-day visit. Dr. Manzi is a world-renowned expert in cardiovascular disease in women with lupus and the director of the Lupus Center at the University of Pittsburgh. Dr. Manzi gave the Lupus Center and general rheumatology staff stimulating lectures on cardiovascular disease risk prevention in lupus patients. She also met with the rheumatology fellows and toured the Lupus Center. In addition, staff benefited from her insights and experience running her own Lupus Center in how to provide state-of-the-art care to our patients. It was an exciting and fruitful two-day exchange.

Patient advisory board

The first meeting of the Lupus Center patient advisory board was held on Thursday, March 12, at Brigham and Women's Hospital. After introductions and an overview of the Lupus Center, participants discussed future goals and plans. On the horizon, the Center hopes to develop a peer-to-peer support program, more educational information and programming regarding healthy lifestyles and complementary modalities, a patient lending library, and more clinical trials. We are also exploring ways to fundraise to support our activities. If you are interested in participating in the patient advisory board or you would like more information, please call Erica Dumas at 617-525-8589.

Updates from the Lupus Foundation of New England

The annual meeting of the Lupus Foundation of New England (LFNE) occurred on March 26 at the Marriott Hotel in Newton. At the meeting, the new president, Joel Weiss, MD, was introduced and our very own Bonnie Bermas, MD, director of BWH's Lupus Center gave the keynote address.

Upcoming events

- The LFNE Gala/Cocktail party will be held early this summer at the Liberty Hotel in Boston.
- The LFNE's annual Walk on the Charles is scheduled for Sunday, September 13, 2009.

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.

LUPUSNEWS Volume 1 / No. 2

Brigham and Women's Hospital
Lupus Center

75 Francis Street
Boston, MA 02115
(617) 732-5515

www.brighamandwomens.org/rheumatology/lupus/

BRIGHAM AND
WOMEN'S HOSPITAL