



Lupus News

Tips and information from the BWH Lupus Center

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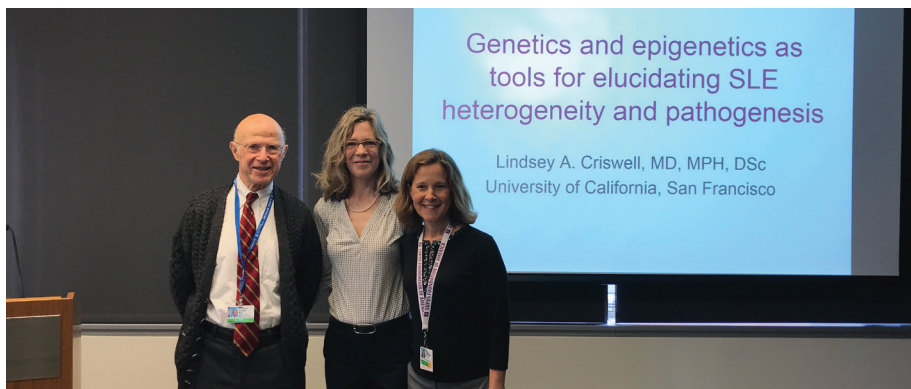
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Drs. Peter H. Schur (L) and Karen Costenbader (R), with Dr. Lindsey Criswell, UCSF Chief of Rheumatology, who delivered the 2018, *Peter H. Schur, M.D. Visiting Lectureship in Lupus* at BWH Rheumatology Grand Rounds.

Unlocking the Meaning of Lupus Lab Tests

Peter H. Schur, M.D.

In patients with systemic lupus, laboratory tests help to determine if an individual has an active inflammatory condition and how well specific organs in the body are functioning. They are often useful in diagnosing lupus and differentiating it from other arthritic conditions, like rheumatic arthritis or scleroderma.

There are several kinds of lupus but the two most common are: (1) cutaneous lupus which only affects the skin and (2) systemic lupus erythematosus (SLE), which can affect the skin and other organs including the kidneys and heart. As a physician considers a lupus diagnosis, they will collect a blood sample and order some important tests. Some examples:

- ANA (Anti-nuclear antibody) test is usually the first one ordered. If the results are positive it may suggest SLE, or that the patient is at moderate to high risk of developing SLE. Additionally, the greater the level of positivity (titer) of the ANA, the greater the likelihood of having SLE. *However, a positive ANA even in high titer is not diagnostic of SLE. It only increases the likelihood, and is found in many other conditions and can mean that the person could have another autoimmune disease!*

As the ANA test does not discriminate which proteins a patient has antibodies to, other tests have been developed that detect antibodies to specific nucleic acids and nuclear proteins. **They are called dsDNA, Sm, RNP, Ro/SS-A, and La/SS-B.**

- Anti-dsDNA antibodies are found in 75% of patients with SLE, and only occasionally in other conditions (like rheumatoid arthritis). Usually, if the levels found over time are increasing, this can suggest that the risk for a flare is higher.
- Anti-Sm antibodies are found in about 25% of patients with SLE, but rarely in other conditions.
- Anti-RNP antibodies are found in about 58% of patients with SLE, but also in patients in patients with other rheumatic conditions.
- Anti-Ro/SS-A antibodies are found in about 40% of patients with SLE (especially those who also have a form of skin lupus).
- Anti-La/SS-B antibodies are found in about 15% of patients with SLE.

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BRIGHAM HEALTH

BRIGHAM AND WOMEN'S
Lupus Center



Lupus News

Brigham and Women's Hospital

Lupus Center

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Boston, MA 02115

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<http://bit.ly/bwhlupuscenter>

Patient Advisory Board Meeting

On Thursday, April 12th, we held our 2018 Patient Advisory Board kickoff meeting! We had seven patient leaders, three physician leaders and two Lupus Center staff in attendance. The meeting was very successful and we are thrilled with the great ideas that were shared. The agenda included:

- Identifying topics for the *Healthy Living with Lupus* community forum on May 19th.
- Reviewing information in the information packets we provide to patients who are newly diagnosed with lupus.
- Updating attendees on our current research and clinical trials, and strategizing about the best ways to keep patients informed about these opportunities.
- Discussing how to enhance our community presence through social media and insignia etc.

With the help of the BWH Lupus Center Patient Advisory Board, we will prioritize our agenda by integrating our patients' invaluable perspective into our day-to-day practices and continue to broaden our community-wide presence.

If you are interested in learning more, please reach out to our Lupus Center coordinator, Corine Sinnette (csinnette@bwh.harvard.edu or 617.525.7054).



Meaning of Lupus Lab Tests (cont.)

Since SLE can affect how well the body's different organs perform, the doctor may ask the patient to complete some additional testing and might recommend specific procedures to evaluate just how well certain organs are functioning. They include:

- Complete blood count (CBC). This test measures different components in the blood such as red blood cells (RBC), white blood cells (WBC), hemoglobin (Hgb), hematocrit (Hct) and platelets. A low WBC is often found in patients with SLE. For example, a very low level (less than 2500) suggests that one has active SLE activity, and at risk for infection.
- Blood Urea Nitrogen (BUN) and Creatinine test how efficient the kidneys are at moving waste and excess fluid from the body.
- Complements (a series of blood proteins) are also often checked. If these levels are low, they may suggest active SLE and inflammation of the kidney.
- Erythrocyte Sedimentation Rate (ESR) and elevated C-reactive protein (CRP)

are used to help detect inflammation that is present.

- Pulmonary Function test (PFT), Echocardiogram (ECHO) and Electrocardiogram (EKG) all measure lung and heart functions respectively.
- Synovial fluid measurements. If a joint is very inflamed there is often an excess amount of fluid. A normal knee typically has about 1 tsp (5ml) of fluid. An inflamed knee can have as much as 100ml. Your doctor may "tap" your knee to drain the fluid and relieve the pressure and pain. The fluid may be sent to the lab to test determine if an infection is present.
- X-rays and MRI (of lungs, heart, joints, bones, brain, abdomen etc.) are sometimes needed to look for infection, inflammation, fractures.

Generally, the physician uses the results of the patient's lab test to help determine how active his/her lupus currently is, and to decide on the best course of treatment and the type of medication that may be best.

Be sure to talk to your rheumatologist if you have any questions or concerns!

You're invited to Healthy Living with Lupus Community Forum

The Brigham and Women's Hospital Lupus Center will co-host our 3rd annual community forum Healthy Living with Lupus with the Lupus Foundation of America, Women of Courage, Inc. and the Boston Arthritis & Lupus Support Group.

Physician experts will present on the roles of the environment and sleep on lupus and provide updates on research studies and clinical trials from the past year. Patient leaders will describe their experiences talking to their communities about lupus. There will be breakout sessions with local lupus support group leaders and members.

Saturday, May 19th 2018
12pm-4pm

Sportsmen's Tennis & Enrichment Center
950 Blue Hill Avenue, Dorchester, MA 02124

For more information, please contact Corine Sinnette: 617-525-7054 | csinnette@bwh.harvard.edu

THIS EVENT IS FREE

Open to patients, family and friends
Parking is available
Lunch will be served



Women of Courage
Lupus Support Group



Ask the Doctor!

Cianna Leatherwood, M.D. answers your questions about lupus and reproductive health

Q: What happens if I have lupus and get pregnant?

Lupus is a condition that predominantly impacts reproductive-age women, and it is common for lupus patients to desire pregnancy at some point in their lives. Pregnancy can present challenges for patients with lupus, but it can be successful with planning and a good partnership between you and your healthcare provider. If you have lupus, there are risks to both you and the baby during pregnancy. For you, there are risks including having a flare, high blood pressure, or going into labor early. For the baby, there is a risk of having low birth weight, being born early before full development, and a risk of heart problems, depending on the type of autoantibodies you have. Therefore, it is important for lupus patients to do as much as they can to have a planned pregnancy. However, almost 50% of pregnancies in the US are unplanned. Birth control is an important tool to help avoid unplanned pregnancy, and to ensure that when pregnancy occurs, it will most likely result in a healthy and happy mother and child.

Q: What things should I consider when thinking about birth control?

There are many birth control options available, but some of them are safer than others for women with lupus. The choice of birth control is driven by the following risks:

(a) Increased risk of flare- for this reason, we recommend that lupus patients

avoid birth control with high concentrations of estrogen, and opt for progestin-based regimens (progestin-only pills or IUD).

(b) Increased risk of blood clot- this is especially important if you have antiphospholipid antibody syndrome.

(c) Interactions with medications- some medications may interact with birth control, so it is important that your physician performs an interaction check.

(d) Increased risk of osteoporosis- some forms (particularly the progestin-only injection) may increase the risk of osteoporosis.

It is important to note that the only method that can prevent the transmission of sexually transmitted infections is a condom.

Q: What kind of birth control options are available for patients with lupus?

There are several options available:

(a) Long-acting reversible contraception (LARC)- These methods can be left in place for months to several years. We often recommend these methods, which include intrauterine devices (IUDs) and implants.

(b) Short-acting reversible contraception- These methods are generally hormone based, with varying concentrations of estrogen and progesterone. Options include oral contraceptive pills, injections, skin patch and an intravaginal ring.



(c) Barrier Methods- this includes condoms, diaphragms and spermicides. These are less reliable methods; however, one advantage of condoms is that this also prevents transmission of sexually transmitted infections (HIV, herpes, chlamydia, gonorrhea, etc.). Diaphragms and spermicides do not prevent sexually transmitted infections.

Q: I haven't decided if I want to have a baby or not. Should I do anything?

There are several questions that only you (and, if applicable, your partner) know the answers to, such as:

-Do you want to get pregnant?

-If you don't want to get pregnant, are you doing anything to prevent it?

-If you do want to get pregnant, when?

-Does your rheumatologist know that you want to get pregnant?

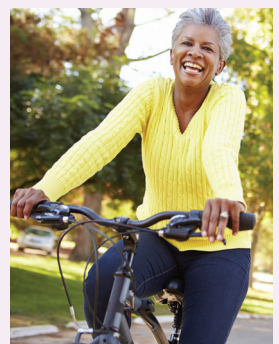
Whatever the answers to these questions, it is important to discuss birth control and family planning goals with your rheumatologist and your gynecologist and to update the conversation regularly. With planning, it is entirely possible for women with lupus to have healthy and happy babies.

Staying Active when you have Lupus!

Exercise has many potential benefits for people living with lupus. Through exercise, you can build stronger muscles, which in turn stabilize joints and decrease pain. Exercise also strengthens the lungs and protects against build-up of plaque in the arteries of the heart. Aerobic exercise can counteract weight gain from steroids. Finally, the endorphins generated by exercise help with mood regulation.

While the idea of exercising may certainly seem overwhelming in the face of lupus-related fatigue, regular exercise has been shown to increase energy and improve sleep quality. In 2011, a study from the University of Alabama demonstrated a 20% reduction in fatigue scores among lupus patients participating in a home-based exercise program for 30 minutes 3 times a week over 10 weeks. More recently, a 2016 study from Northwestern University School of Medicine showed that more physical activity was associated with less fatigue in lupus patients. Other studies have also demonstrated that exercise may decrease systemic inflammation in people with lupus.

There are many potential joint friendly activities: walking, bicycling, swimming, elliptical machine, low impact aerobics, water aerobics, pilates, and yoga, to name a few. Benefits are greatest with at least 30 minutes of exercise 3-5 times a week, ideally a mix of aerobic exercise and strength training. But remember to wear sunscreen and sun-protective clothing if spending time outside!





The BWH Lupus Center is the clinical home of our extensive BWH Lupus Program, focusing on advancing the understanding and care of patients with this complex autoimmune illness. Our Lupus Center clinic is located in the Hale Building for Transformative Medicine, inside the Orthopaedic and Arthritis Center on the 2nd Floor.

At the BWH Lupus Center, we ensure rapid access appointments for our patients and timely communication with their care providers. We have fourteen board-certified rheumatologists who care for more than 800 lupus patients annually including children and youth transitioning to adult care. Our physicians also work closely with other BWH specialists.

We are committed to providing our patients with comprehensive and cutting-edge consultative care. We are also dedicated to identifying and addressing racial, ethnic and socioeconomic disparities in lupus care and outcomes. This commitment can be seen through our clinical work, our research, and our community-based interventions and educational programs.

To learn more about the BWH Lupus Center's clinical services and ongoing research, visit us at: <http://bit.ly/bwhlupuscenter>

Lupus Center Physicians and Staff

Front from L to R: Cameron Speyer, Paul Hoover, John Coblyn, Cianna Leatherwood, Peter Schur, Susan Ritter, Laura Tarter, Sara Tedeschi, Corine Sinnette, Elena Massarotti

Back from L to R: Courtnie Phillip, Nyla Brewster, Sarah Chen, Shreya Patel, Nicole Yang, Nancy Shadick, Karen Costenbader, Candace Feldman, Helena Jonsson, Deepak Rao, Selena Huang



Research Spotlight



LUCIN—Clinical Research Network

The BWH Lupus Center is pleased to participate in the Lupus Research Alliance's clinical research network called LUCIN (Lupus Clinical Investigators Network). We are one of many nationally renowned lupus centers represented in the network. A major goal of LUCIN is to facilitate lupus clinical trials and studies, including trials of new therapies and to find better treatment options for lupus patients. To learn more, you can contact Corine Sinnette, csinnette@bwh.harvard.edu

Physical and Mental Health and Medication Use among Patients with Lupus

We are conducting a research study funded by the Rheumatology Research Foundation to understand changes in mental and physical health and medication use among patients with lupus over 6-8 months. We are looking for participants who have been diagnosed with lupus and are currently taking a lupus medication. Participants will complete a total of

3 visits and every effort will be made to have these visits coincide with regularly scheduled rheumatology appointments. Participants will receive either a parking voucher or a cafeteria voucher for each completed visit. For more information about this study, please contact Courtnie Phillip, cphillip1@bwh.harvard.edu