



# Lupus News

Tips and information from the BWH Lupus Center

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## Introducing: Laura Tarter, M.D.



We are thrilled to announce Dr. Tarter has recently joined the BWH Lupus Center faculty. She received her M.D. from Harvard Medical School, and completed her residency in internal medicine and fellowship in rheumatology at Brigham and Women's Hospital and the University of California, San Francisco. She was subsequently on faculty at Stanford University, where she served as director of the Stanford Lupus Clinic. She is currently accepting new patients!

## Why are my fingers changing color in the cold?

Cianna Leatherwood, M.D. explains Raynaud's phenomenon and what you need to know for winter.

Raynaud's phenomenon is a condition where the fingers or toes change color due to loss of blood flow, usually in response to exposure to cold temperatures. The color change of Raynaud's is due to vasospasm (narrowing), of the blood vessels that supply the fingers and toes. When the blood supply to these areas decreases, the fingers and toes may turn white or purple/blue. The affected body part may also become numb, painful, or start to tingle. Once blood flow returns, the body part may burn or turn red. This decreased blood supply can also occur in the ears, nose or lips. These symptoms can last anywhere from minutes to hours. People who

experience Raynaud's phenomenon frequently note that it becomes more prominent in the winter, but some experience it with as little activity as reaching in the freezer for frozen foods. Occasionally, Raynaud's can also occur without significant exposure to cold temperatures. Generally, it occurs more frequently in cold areas (i.e. it is more common in Massachusetts than California) and is more common in women.

There are two types of Raynaud's: primary and secondary. Primary Raynaud's occurs without any association with another condition. Approximately 5% of the general



## Healthy Living with Lupus Community Forum

Our 2nd annual Healthy Living with Lupus Community Forum was a huge success with over 50 patients and family members in attendance! On June 10th, 2017, the Brigham and Women's Hospital Lupus Center co-hosted the event with the **Lupus Foundation of America** and the **Women of Courage**, a local organization dedicated to supporting and empowering Women of Color living with lupus. It was held at the Sportsmen's Tennis & Enrichment Center in Dorchester, Massachusetts. We heard from diverse speakers, each with different tips on healthy living with lupus. Lisa Adelman, a Wellness Coach and Reiki Master at BWH, discussed patient empowerment, meditation, and stress management. BWH Lupus Center faculty, Dr. Feldman and Dr. Costenbader, presented updates on the group's current lupus research and clinical trials. Brigham and Women's Hospital nutritionist, Michele Ries, discussed how to eat healthy with lupus and Dr. Judith Puckett, a psychiatrist at Massachusetts General Hospital spoke about managing depression and anxiety. Following the speakers, a patient-led panel discussed how to talk to others about your lupus, and the event closed with a breakout session hosted by the Women of Courage Support Group. We look forward to co-hosting the event again next year!

## Raynaud's continued

population has this, and it is more common in people who smoke or work with their hands. It is also observed to be more common in people with a family history of migraines, or a history of Raynaud's itself. Primary Raynaud's usually starts between the ages of 15-30. Secondary Raynaud's presents like Primary, the difference being it is associated with another condition such as connective tissue disease (like systemic lupus erythematosus or scleroderma), medications, occupations, blood vessel abnormalities or other anatomical abnormalities (like carpal tunnel syndrome). It usually starts between the ages of 30-40.

In some cases, Raynaud's can be so severe that people develop ulcers on their fingers and toes. These individuals must follow up regularly with a physician. The majority of the time, however, Raynaud's is manageable despite being very aggravating. Secondary Raynaud's can improve by treating the underlying associated conditions. Regardless of whether it is primary or secondary, here are

some things you can do to reduce the frequency of your symptoms:

- (a) stop smoking;
- (b) reduce exposure to the cold by wearing gloves, thick wool stockings, or using chemical handwarmers;
- (c) avoid chemicals that can cause blood vessels to narrow such as caffeine, beta-blockers, certain migraine medications and certain decongestants;
- (d) avoid taking stimulant medications used to treat attention deficit disorders;
- (e) reduce your stress, as stress can trigger a Raynaud's episode.

If the above measures are not enough to control the symptoms, there are certain medications such as calcium channel blockers and other therapies that can be prescribed by your physician to keep your blood vessels from narrowing in cold weather. As a final measure, there are surgical procedures that can be helpful in extreme cases. Be sure to talk to your rheumatologist if you have any questions or concerns.

### Do you or someone you know have lupus? Are you interested in sharing information about lupus with your neighborhood?

Consider joining "Lupus Conversations" to be a community leader! We are recruiting African American men and women in the Greater Boston area, 18 years or older, to be community leaders spreading the word about lupus. Lupus rates are high among African Americans and the disease can be more serious. By participating in "Lupus Conversations," you will join a community that advocates for patients with lupus to get the excellent health care that they need and deserve!

To participate, you will be asked to attend 3 one-hour educational sessions, and share information about lupus with individuals in your neighborhood. You will be compensated for your time (up to \$200) and do not need to have lupus to join. This study is supported by the Office of Minority Health and is a collaboration between Brigham and Women's Hospital Lupus Center, Women of Courage Support Group, and Northwestern University, Feinberg School of Medicine. For more information, contact Courtnie Phillip at (617) 732-6356 or [cphillip1@bwh.harvard.edu](mailto:cphillip1@bwh.harvard.edu).

**Q: Should I get a flu (influenza) shot?**

Yes, you should get a flu shot. Influenza is not “just a cold” -- it is a serious viral infection that kills thousands of people in the United States every year. Many lupus patients take medications that lower their immune systems, which makes them more likely to become seriously ill from influenza. Getting an influenza vaccination is the best thing you can do to protect yourself, and you should encourage those around you to get vaccinated as well. The flu vaccine is not 100% effective at preventing the flu, but even if you do get the flu, it will be milder if you had the vaccine. You cannot get the flu from the flu shot because the shot does not contain live virus. Most people don't have any problems with the flu shot, but some people get achy pain at the site of injection that lasts for 1-2 days. The flu shot is safe even if you are taking medications that suppress the immune system. (There is also a nose spray version of the vaccine, but this form DOES contain live virus, and it is therefore not recommended for lupus patients.)

**Q: How does the influenza vaccine work?**

The influenza vaccine contains dead influenza virus particles. Because the virus is dead, the vaccine cannot give you the flu. Your immune system produces antibodies in response to the dead virus particles. If your body encounters the real virus at some later point in time, the antibodies attack the virus and help your immune system to get rid of the virus very quickly, before you feel sick.

**Q: Are there other vaccines that I should get?**

Most of us received a number of vaccinations as children to prevent diseases like measles or chicken pox, but there are a few to think about as an adult as well. Vaccinations help to prevent infections, and this is especially important in patients with lupus, who often have weak immune systems.

1) Patients taking medications that

The BWH Lupus Center faculty showed their support at the Lupus Foundation of New England's 25th annual Walk on the Charles.



## Ask the Doctor!

Helena Jonsson, M.D., Ph.D. answers your questions about vaccines and lupus.

suppress the immune system (such as mycophenolate mofetil (CellCept), rituximab (Rituxan), and others) should talk to their rheumatologist about vaccinations for pneumococcal pneumonia, a severe lung infection. This vaccination helps prevent infection by a type of bacteria called *Streptococcus pneumoniae* (often called “Strep pneumo” for short), which can cause severe, sometimes fatal, pneumonia. There are two vaccines, Prevnar and Pneumovax, that cover different bacterial strains of Strep pneumo, and boosters are given every 5 years.

2) Young adults (less than 26 years old) should talk to their primary care physician about the human papilloma virus (HPV) vaccine, which can help prevent cervical cancer and genital warts. Cervical cancer is more common among patients with lupus than the general population, so preventing this type of cancer is important. The HPV vaccine is safe, even if you are taking medications that weaken your immune system.

3) Older adults (over 60 years old) should talk to their rheumatologist about the shingles (zoster) vaccine, which can help prevent painful

outbreaks of shingles rash. This vaccine is a live vaccine (meaning that it contains live virus), so it may not be safe for patients taking strong immunosuppressing medications. This includes many lupus patients. Talk to your rheumatologist about whether this vaccine is safe for you.

4) There may be other vaccines that are recommended for you, such as a tetanus booster. Ask your doctor for more information.

**Q: Are there any vaccinations that I should NOT get?**

Many patients with lupus take medications that weaken the immune system. Patients with weakened immune systems should not receive “live” vaccines, i.e. vaccines that contain live virus. Examples of live vaccines include MMR (measles, mumps, and rubella), which is recommended for all children but not for adults. Some vaccines that are recommended for foreign travelers, such as the yellow fever vaccine, are not safe for patients with weakened immune systems. Talk to your rheumatologist if you have any questions about whether a particular vaccine is safe for you.



# Lupus News

## Brigham and Women's Hospital Lupus Center

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## Research Corner



The BWH Lupus Center is pleased to participate in the Lupus Research Alliance's new 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. We are currently recruiting for a study involving the usefulness of an app with an iPhone to collect patient related data among individuals diagnosed with lupus. Our hope is that the app can be used in clinical trials going forward, and may also be a useful way for lupus patients to monitor lupus symptoms. The main goal of LuCIN is to find better treatment options for lupus patients and hope you can assist. For more information on this study and others, contact Corine Sinnette at [csinnette@bwh.harvard.edu](mailto: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 sets of surveys either online or at the time of your rheumatology appointment. Participants will receive either a parking or cafeteria voucher for each completed set of surveys. For more information about this study, contact Shreya Patel at (617) 525-8785 or [spatel104@bwh.harvard.edu](mailto:spatel104@bwh.harvard.edu).

## Congrats, Karen!



Our very own Karen H. Costenbader, M.D., Director of the Lupus Program at Brigham and Women's Hospital in Boston and Professor of Medicine at Harvard Medical School, has been appointed Chair of the Lupus Foundation of America's Medical and Scientific Advisory Council. Dr. Costenbader will lead a multi-disciplinary group of medical experts to address unmet needs in research and professional development efforts related to lupus. Dr. Costenbader will work to expand the Foundation's strategic partnerships with key opinion leaders in lupus around the world to increase the Foundation's reach and growing impact in efforts to help people with lupus now.