



Lupus News

Tips and information from the BWH Lupus Center

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To learn more about our Lupus Research Program:

<https://lupus.bwh.harvard.edu/>

Lupus and the COVID Vaccine

by Emma Stevens

The American College of Rheumatology (ACR) released vaccine guidance for rheumatology and immunosuppressed patients in March of this year. A panel of specialists including rheumatologists, infectious disease specialists, and other public health experts developed these recommendations alongside current understandings of COVID-19 vaccines. It is important to note that this guidance is a "living document." As the situation evolves and research continues, the guidance will adjust with it. It is important to discuss all medical decisions with your rheumatologist.



The current ACR guidelines encourage all rheumatology patients, including all lupus patients, to receive the COVID vaccine as soon as they are eligible and indicate that there is "no evidence to support a concern regarding the use or timing of immunomodulatory therapies in relation to vaccine safety." There is also no current evidence that one vaccine is any better or worse than any other for patients with autoimmune diseases or on immunosuppressant drugs, so whichever vaccine is available first is the one people should get. That being said, it is recommended that all patients talk to their doctors about the timing of the vaccine and their medication dosing, especially those on rituximab, because it is a long acting medication, dosed every 4-6 months usually.

Known vaccine side effects include sore arm, redness at the injection site, fatigue, low grade fevers, headaches, joint and muscle pains. Not everyone gets all of these, but when they do occur, they can last 1-2 days. Talk to your doctor if your symptoms are more severe or go on longer than that and definitely before self-treating for a flare of your lupus symptoms, which could be similar. We do not yet know how long the current vaccines will protect against COVID-19, how good they will be against the COVID-19 variants from the UK, Brazil and other places that are circulating, nor if we will have tests to see whether we need revaccination or booster vaccine injections in the future.

Virtual Resources for Lupus Patients

Foundations and support groups at the local and national levels adjusted to the pandemic by expanding their virtual offerings and online educational resources. The Lupus Foundation of America (LFA) website recently published links to support groups in the New England Area who are currently holding virtual events and regular meetings. The "find help" section of the page features links to online communities, virtual resource centers and other virtual support resources available to the lupus community.

In addition, the LFA website offers educational videos in their "resource library" that includes information on a wide range of subjects from the COVID-19 vaccine and lupus, to the effects of lupus on the body, to toolkits for caregivers.

To supplement these virtual resources, the LFA is also hosting more events in 2021. Upcoming events include a talk on lupus and the heart in June and the 2021 Boston Lupus Walk, which will be held virtually on October 16th, 2021. More information on these events can be found on the LFA website (lupus.org). Feel free to check out our website (lupus.bwh.harvard.edu) for more resources, ongoing studies and upcoming events as well.

BWH Lupus Studies

Would you like to be directly contacted to participate in BWH Lupus Studies? If so, email please email our study staff **Jack Ellrodt** at jellrodt@bwh.harvard.edu.

BWH Lupus Patient Assistance Fund

The BWH Lupus Patient Assistance Fund is available to help BWH lupus patients receive the care they need and ensure that medications and hospital visits are not an additional burden to these patients or their families. The fund provides aid in many forms including medication and laboratory co-pay assistance, transportation to and from appointments, parking and grocery vouchers.

As the pandemic has been a source of financial strain for many, we hope the fund can continue to be a useful resource for the lupus community going forward. Please feel free to reach

out to **Jack Ellrodt** (jellrodt@bwh.harvard.edu) if you have any further questions or talk to your treating rheumatologist here at the Brigham.

The generosity of our donors combined with the clinical efforts of our outstanding providers and researchers helps improve the lives of those living with lupus. We also invite you to join our team at The Patient Assistance Support Fund for Lupus and support these patients and their families in any way you can. For more information about our research program and clinical services or how to donate, please visit our BWH Lupus Program website.

BWH Lupus Program Speakers

Although COVID 19 has hampered our ability to meet in person, we have been able to connect with colleagues from afar and invite lupus experts from around the world to participate in our regularly scheduled lupus conferences. In fall 2020/winter2021, we have "hosted" many lupus experts in zoom conferences:

Jane Salmon, MD, Hospital for Special Surgery, NY - *Lupus and Antiphospholipid Antibodies in Pregnancy*
 Richard Furie, MD, Northwell Health, NY - *Clinical Trials in Lupus*
 David Pisetsky, MD, PhD, Duke University, NC- *Microparticles and Autoantibodies in Lupus*
 David Isenberg, MD, FRCP, FA MS, University College London, United Kingdom- *Lupus Nephritis Cases*

Upcoming Events

Liz Lightstone, MA, MBBS, PhD, Imperial College London, United Kingdom- the Peter H. Schur, MD Visiting Professor in Lupus on **April 29**. She is a nephrologist and will talk about current and coming management of Lupus Nephritis.

We also look forward to hosting Maria Dell'ara, MD, from University California San Francisco, CA - who has been postponed until 2022, perhaps to have her visit in person.

2021 Lupus Scientific and Patient Education Virtual Symposium sponsored by the Lupus Foundation of New England (LFNE), **May 6th 2021**, 12:30-6:30pm. RSVP at 1-977-NO LUPUS or www.lupusne.org

"Community Conversations" **May 20, 2021** at 7 pm through Sportsmen's Tennis and Enrichment Center, 950 Blue Hill Avenue, Dorchester, MA. The event will be hosted virtually at 7:00 pm and will feature Dr. Karen Costenbader, Dr. Candace Feldman, Dr. Jessica Williams and Gail Granville, and other lupus patient advocates and community leaders. The discussion will focus on COVID-19 vaccines for lupus patients. Dr. Richard Joseph will moderate the discussion. Check our website: lupus.bwh.harvard.edu for details and the link.

BWH Lupus Studies

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.

Would you like to be directly contacted to about BWH Lupus Studies? If so, please email **Jack Ellrodt** (jellrodt@bwh.harvard.edu).



Physician Spotlight — Dr. Helena Jonsson

The BWH Lupus Program would like to highlight **Dr. Helena Jonsson** for her tremendous contribution to our understanding of COVID-19, its treatments and how it affects people with rheumatic and autoimmune diseases. Dr. Jonsson is a rheumatologist who sees patients in the BWH Lupus Center. She completed her M.D. and Ph.D. in immunology at Washington University School of Medicine and trained in internal medicine and rheumatology here at BWH. Her research is in autoimmunity and immunology and focuses on the role of CD8 T lymphocytes in lupus, rheumatoid arthritis (RA) and other rheumatic autoimmune diseases.

Dr. Jonsson is the director of the COVID Rheumatology program, helping the section understand COVID, vaccines, and clinical guidance. We are so thankful for all her hard work and effort helping us to understand this pandemic and keep the patients safe. Thank you Dr. Jonsson!



LUPUS LIGHTS
NEW ENGLAND

BWH/ LFA Lupus Lights NE Peer Support Group

Please join us at our next Lupus Lights NE virtual meeting! Lupus Lights NE is a peer-led support group for patients and families/caregivers impacted by lupus. This diverse group connects monthly in a relaxed manner to listen, ask questions, exchange tips, and hopefully laugh a little. Lupus Lights NE is sponsored by the Lupus Foundation of America and supported by BWH Lupus Center. For more information or to inquire about the next meeting please contact **Dawn Peters** or **Kelley Keefe** at lupuslightsne@gmail.com.