



# Lupus News

Tips and information from the BWH Lupus Center

## Contact Us:

Phone: 617.732.5515

Fax: 617.732.5766

<http://bit.ly/bwhlupuscenter>

Karen H. Costenbader, M.D., M.P.H.

*Director, Lupus Program*

Elena M. Massarotti, M.D.

*Director, Clinical Trials in Lupus*

Candace H. Feldman, M.D., M.P.H.

*Director, Community Outreach  
and Patient Engagement*

Laura Tarter, M.D.

*Director, Pregnancy and  
Reproductive Health Program*

Peter H. Schur, M.D.

*Director Emeritus*

Jonathan S. Coblyn, M.D.

Patricia Fraser, M.D.

Deepak Rao, M.D., Ph.D.

Susan Y. Ritter, M.D., Ph.D.

Nancy A. Shadick, M.D., M.P.H.

Paul Hoover, M.D., Ph.D.

Derrick J. Todd, M.D., Ph.D.

## Brigham and Women's Hospital

### Lupus Center

60 Fenwood Road,  
Boston, MA 02115

#### To support us:

[https://tinyurl.com/  
DonateBWHLupusCenter](https://tinyurl.com/DonateBWHLupusCenter)

**DonateBWHLupusCenter**

#### To learn more about our Lupus Research Program:

[https://lupus.bwh.harvard.  
edu/](https://lupus.bwh.harvard.edu/)

## BRIGHAM HEALTH

BRIGHAM AND WOMEN'S  
Lupus Center

## Lupus and COVID

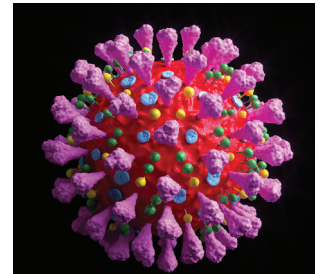
by Helena Jonsson, M.D., Ph.D

During the COVID-19 pandemic, there was an international shortage of hydroxychloroquine (HCQ or Plaquenil), an essential medication in the treatment of lupus and many other rheumatic autoimmune diseases. In patients with lupus, it reduces flares, organ damage, pregnancy complications, and is also the only medication proven to improve survival. Studies have shown that when lupus patients stop taking their HCQ for as short as two weeks, even when their disease has been stable, their lupus can flare. All lupus patients should be taking HCQ unless there is a clear reason not to.

HCQ as an unproven therapy for COVID-19 was initially supported by preliminary data early in the pandemic including a few tissue culture experiments demonstrating HCQ anti-viral activity and flawed reports on a small number of patients. Despite this, HCQ was being widely touted as a potential therapy for COVID-19 including being called a "miracle drug" during a presidential press conference. In March 2020, the supply of HCQ, which has few regular manufacturers, drastically declined due to people stockpiling, a surge in off-label use, and misuse in the medical community as well.

The supply was also being diverted to nearly two hundred different HCQ COVID-19 clinical trials. However, thus far, most of the completed trials have failed to show a benefit from HCQ in patients with COVID-19 or post-exposure to prevent COVID-19. Studies have also been halted because of concerns about potential heart rhythm problems especially when HCQ is taken in combination with other common medications such as antibiotics and anti-depressants. Subsequently, in April 2020, the Food and Drug Administration issued a warning against the use of HCQ for the treatment of COVID-19 in non-clinical trial settings and in some countries, the use of HCQ in COVID-19 patients is now prohibited.

Although the threat of future HCQ shortages is less likely, HCQ prescribing for COVID-19 patient may continue. The American College of Rheumatology (ACR) issued a statement supporting the allocation and protection of HCQ supply to patients with lupus and other rheumatic autoimmune diseases who need it. Check out this website for more information by the ACR: [https://www.rheumatology.org/Portals/0/Files/  
Guiding-Principles-Scarce-Resource-Allocation-During-Covid-19.pdf](https://www.rheumatology.org/Portals/0/Files/Guiding-Principles-Scarce-Resource-Allocation-During-Covid-19.pdf).



## BWH Lupus Studies

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 participate in BWH Lupus Studies? If so, email please email our study staff **Jack Ellrodt** [jellrodt@bwh.harvard.edu](mailto:jellrodt@bwh.harvard.edu) or **Emma Stevens** [estevens5@bwh.harvard.edu](mailto:estevens5@bwh.harvard.edu).



# Telemedicine

by Susan Ritter, M.D., Ph.D.

The use of telemedicine has risen exponentially during the COVID-19 pandemic as a way to access care. While telephone calls can be OK, it is much preferred to use a video visit so your doctor can see you and do a virtual examination if needed.

What can you as a patient do to improve the experience and make it feel more like an office visit? First, you want to treat it like it is an appointment. Schedule it in your calendar, make sure you “arrive” online early so you can troubleshoot any internet or access problems. There may be instructions available before the visit to help you know if you need to download additional software or programs. Many platforms work on smart phones, tablet devices and laptops—so pick the one you feel most comfortable with and be sure it is charged. If there is someone in your home who is tech savvy, you may have them available to help you get logged in and started the first time. Also, having good lighting and a quiet environment will help you focus to see and hear each other.

Just like for any appointment, be prepared. Know what medications you are taking (you can have your medicines in front of you!) and any questions you have. If you need labs done, be sure to strategize with your doctor where, when and how these will be done. Also, if refills are needed these can be done during the visit. If you have a physical finding that you cannot show your doctor during the visit, you may be able to take a photo with your phone and send it through the Patient Gateway system. Finally, make sure you know when you should follow-up again and how to make a follow-up appointment.

During these trying times, it is more important than ever to stay close to your support team, and telemedicine gives you an additional way to do this from the comfort and safety of your own home/work environment.

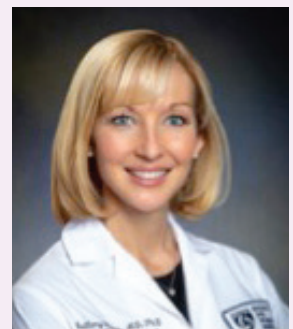


## Remember

- **Schedule it in your calendar**
- **“Arrive” early**
- **Choose a comfortable environment (someplace quiet with good lighting)**
- **Know your current medications and need for refills**
- **Be prepared with questions for your provider**

## Introducing Brittany Weber

The BWH Lupus Center would like to welcome **Dr. Brittany Weber** to the team. Dr. Weber is an advanced cardiovascular fellow at Brigham and Women’s Hospital. She completed her M.D. and her Ph.D. in immunology at the University of Pennsylvania and then trained in internal medicine and cardiology at BWH, where she served as chief medical resident. Her clinical and scientific interests lay at the intersection of her two passions - immunology and cardiology. Here, she specializes in cardio-rheumatology, focusing on the role systemic inflammation plays in vascular health, cardiac structure and function. She is interested in the relationship between the systemic inflammation in lupus and increased risk of cardiovascular disease, and what can be done to lower the risk of heart disease. In her free time, she loves to spend time with her family, travel, and be outdoors!



## Lupus Lights Virtual Meeting

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](mailto:lupuslightsne@gmail.com).

**LUPUS LIGHTS**  
NEW ENGLAND