BRIGHAM HEALTH
BRIGHAM AND WOMEN'S
Lupus Center

Spring/Summer 2019

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.

Managing Lupus in the 21st Century

Lupus is a complex, and sometimes mystifying illness. Despite many advances in the field of rheumatology and lupus research, there is unfortunately still no cure. Today, researchers, providers, caregivers, and patients strive to offer not only hope, but also tangible mechanisms to fund research, enhance education, and broaden support for those who suffer from lupus. Advances in technology and the proliferation of social media platforms have drastically increased the number of resources available to the lupus community. In this issue of *BWH Lupus News*, we have rounded up some of the most popular online disease management and support tools for you! While we are not endorsing any of these specific resources, we have done our best to verify their legitimacy. We hope you find some of these useful as you manage your illness, or as you take care of someone who may be diagnosed with lupus. Be sure to always discuss any medication or lifestyle changes with your treating rheumatologist!

The Lupus Foundation of America (LFA) and Lupus Research Alliance (LRA) are two prominent organizations in the field. Founded in 1977, the LFA has local chapters throughout the United States and offers a few different programs to engage members of the lupus community. Their website has a wealth of information. In collaboration with the Centers for Disease Control and Prevention (CDC), the "National Resource Center on Lupus" is described as a "living collection of up to date resources and information on lupus." This information is relevant to those living with lupus as well as caregivers, parents and professionals. More recently, they launched "The Expert SERIES," an educational video series from leading global lupus experts. Users can subscribe to the series to get updates and learn when new segments are added. The LFA also sponsors "LupusCONNECT™ " a free online community for people living with lupus. It is an online platform where people can ask questions, reply, share experiences, find emotional support and discuss practical tips for coping with lupus.

The Lupus Research Alliance was established in 2016 merging the Alliance for Lupus Research, the Lupus Research Institute, and the S.L.E. Foundation. This group focuses on fundraising for research and raising awareness and is the mother organization of LuCIN (Lupus Clinical Investigators Network), an academic group focused on advancing clinical trials. For patients, information across a spectrum of categories is easily available; of note, there is a neat 'Glossary' of terms used frequently, financial resources and international organizations that are partnered or affiliated with LRA.

In addition to these, the World Lupus Foundation is a federation of patient global organizations, that promotes lupus awareness and sponsors World Lupus Day. Their website is a great place to start gathering information on patient support groups around the world. Many of these larger organizations also have a prominent social media presence. The ready availability of our phones and tablets has made it easier for just about everyone to access platforms like Facebook, Twitter or Instagram. Some individuals with lupus have curated large audience followings successfully sharing their advocacy, struggles, social and emotional support to others in the lupus community. Social media has been an invaluable tool for raising awareness and forming a community to fight against lupus. The proliferation

Continued on page 2

Brigham and Women's Hospital
Lupus Center
60 Fenwood Road, Boston, MA 02115

To support us:
https://tinyurl.com/DonateBWHLupusCenter

To learn more about our Lupus Research Program:
https://lupus.bwh.harvard.edu/

BRIGHAM HEALTH
BRIGHAM AND WOMEN'S
Lupus Center

Managing Lupus in the 21st Century (cont.)

of information across the internet has tremendous potential, but, as always, it is important to be a critical and informed reader while using these sources. The next page highlights several websites, social media pages and other online resources that may be helpful. Again, we have done our best to find legitimate and reliable resources but do contact your primary healthcare provider or treating rheumatologist with any questions regarding this information.

Local Resources:

The Lupus Foundation of New England is a local non-profit that works with a variety of sponsors to "educate and support people with lupus, promote awareness and fund scientific research that will lead to better treatments and ultimately a cure." Contact information for local support groups is available on their website. Vozzy's Legacy is a grassroots organization that raises money for lupus research and provides financial and education assistance to individuals diagnosed with lupus. This group offers healthcare and financial aid to lupus patients as well as a scholarship program for lupus patients looking to attend 2- or 4-year universities. Vozzy's Legacy also hosts several events in New England including a charity golf tournament each year.

The tables below contain links to these resources. We hope you find them useful. Please let the BWH Lupus Center know of other lupus resources you love!

National and Local organizations	Website
Lupus Foundation of America	https://www.lupus.org/
Lupus Research Alliance	https://www.lupusresearch.org/
World Lupus Federation	http://worldlupusday.org/
Lupus Foundation of New England	https://lupusne.org/
Vozzy's Legacy	http://www.vozzyslegacyforlupus.com/index.html

Social Media 'handle'	Platform
@goldenmoe	Instagram
@thelupustrainer	Instagram
@LupusFoundationsofAmerica	Facebook
@lupusfoundation	Twitter
@lupusresearchalliance	Instagram
@lupusorg	Twitter, Instagram
@LupusResearch	Twitter
@lupusladies	Twitter

Other Resources:

Collaboration with The American College of Rheumatology and Lupus Foundation of America.	https://befiercetakecontrol.org/
The Lupus Initiative.	https://thelupusinitiative.org/patients-caregivers/selfmanagement/
Office on Women's Health.	https://www.womenshealth.gov/lupus/lupus-resources
Lupus Sistas.	http://www.lupussistas.com/
Lupus Chick.	http://lupuschick.com/
GSK: Us in Lupus.	https://www.usinlupus.com/
Lupus Minder App/HSS LupusMinder® Mobile App for People With Lupus	https://www.hss.edu/SLEWorkshop.asp
Office of Women's Health.	https://www.womenshealth.gov/lupus
Centers for Disease Control and Prevention.	https://www.cdc.gov/lupus/facts/detailed.html
Lupus Connect.	https://www.lupus.org/resources/lupusconnect

BWH Lupus Center Events

Community Forum Recap

Our 4th annual **Healthy Living with Lupus Community Forum** on June 1st was a huge success! Over 50 patients, family members and friends of the local lupus community joined us at the Sportsmen's Tennis & Enrichment Center in Dorchester, Massachusetts. This year's event was cohosted by Brigham and Women's Hospital Lupus Center, **the Lupus Foundation of America**, the **Women of Courage** support Group and **Boston Arthritis and Lupus Support Group**. The forum featured updates on Lupus research and Lupus related initiatives as well as a number of informational breakout sessions for those in attendance. Following introductions by Sara Bentley of the Lupus Foundation of America and Dr. Candace Feldman of Brigham and Women's Hospital, Dr. Elena Massarotti, also of BWH, provided a succinct overview of current clinical Lupus Nephritis and Epidemiology studies in the field. Dr. Massarotti was followed by Drs. Paul Hoover and Dr. Helena Jonsson who updated the forum on current efforts in Lupus Basic Science and translational studies. After discussion of current clinical, basic and translational research in the field, Dr. Jessica Williams introduced current efforts to reduce avoidable outcomes in Lupus. Dr. Williams presentation was complemented nicely by Dr. Laura Tarter's talk on reproductive health, Judith Siegel's talk on the empowerment of men with Lupus and Dr. Candace Feldman's review of manifestations of Lupus in men and outcomes for these patients. The forum concluded with a series of breakout sessions held by the Women of Courage support group, Boston Arthritis and Lupus Support Group and BWH Lupus physicians. Thank you to all who attended, and we look forward to co-hosting the event again next year!

Upcoming Local Events

August 18, 2019
New Balance Falmouth Road Race
Falmouth, MA

September 22, 2019
27th Annual Walk on the Charles
Lupus Foundation of New England
Brighton, MA

Date TBD
11th Annual Runway for a Cure
Lupus Research Alliance
Providence, RI

October 19, 2019
2019 Walk to End Lupus Now
Lupus Foundation of America
Boston Common, Boston, MA

Championing Lupus Awareness

Caroline Higgins (L), Dawn Peters and Kelly Keefe (R)

On March 4th and 5th of last spring, three of our patient advisory board members joined 350[1] other lupus advocates at the 2019 National Lupus Advocacy Summit in Washington D.C., an event organized annually by the Lupus Foundation of America. One of the event goals is to continue to urge Congress to increase funding for lupus research and support educational programs. It is also an opportunity for individuals in the lupus community to meet others who are connected through this disease and share the challenges of living with such an unpredictable illness. We asked board members Caroline, Dawn and Kelly to share their experience roving around the Capitol!

*"*We were thrilled to attend the 2019 lupus summit! We discussed attending at our last patient advisory board members and decided that the three of us would attend together. Caroline had never participated; she was excited about it and knew almost immediately that she wanted to go. As members of the BWH Lupus patient advisory board, we feel a responsibility to advocate for ourselves and others affected by this disease, and this was a wonderful opportunity in which to participate *en masse* with so many others."

"We laughed together as we cruised around The Hill in purple capes. It was a treat being with such an inspiring, strong, determined, and motivated group! We-patients, doctors, researchers and advocates- listened, shared, and learned from each other. We also learned a tremendous amount about the disease and the challenges researchers face in finding new treatments. At the end of the trip, we left the summit inspired by everyone we met and hopeful that our voices were heard."

"When we met our local representatives over the two-day period, we each shared our stories, detailing the many challenges we've faced living with this disease (or being a caregiver of someone with the disease). Through our stories, we demonstrated how lupus can affect any organ or tissue from skin to joints to heart to kidneys at any time. We showed them the many pills we need to take to get us through the day. And we let them know that only one drug has been approved for the disease in 50 years. We asked them to fund programs aimed to raise awareness, improve the time to diagnosis, and hopefully find a safe, tolerable, effective drug to better treat or cure the disease. Hopefully, our stories made an impact."

*Dawn and Kelly also manage the @lupusladies Twitter account

Reference:
i. https://www.lupus.org/advocate/2019-national-lupus-advocacy-summit

Ask The Doctor!

Lupus patients are especially susceptible of early heart disease. Cardiovascular disease is the number one cause of death in patients with longstanding lupus.

Q: What can I do to decrease my chances of having heart disease?

You can improve your heart health through several lifestyle preventive measures:

Avoid smoking. Among other harmful effects (higher lupus disease activity, lung disease, and cancer risks), smoking increases the risk of heart attacks and strokes. If you currently smoke, you can greatly reduce the chances of having a heart attack or stroke by quitting. If you already have history of a heart attack or stroke, you can still lower your risk of having another event by quitting. 1-800-QUIT-NOW is a national tobacco quit line which offers individual counseling to help you get started.

Be active. The American Heart Association recommends regular aerobic exercise of at least 150 minutes a week combined with muscle-strengthening activities to improve your overall and cardiovascular health. Although this may seem daunting at first, you can start slow and work up to your goal. If you have difficulty with activity due to joint pain, it may be helpful to work with a physical therapist to strengthen your muscles and improve your mobility.

Consume a heart healthy diet. In addition to increasing your intake of vegetables and fruits, we recommend a low-fat and low-cholesterol diet which will also help lower your weight. Eating a low salt diet is also important as salty foods can worsen your blood pressure which can increase your risk of heart disease.

For more tips, visit: **https://www.heart.org/en/healthy-living/healthy-eating/eat-smart/nutrition-basics/aha-diet-and-lifestyle-recommendations**

Take your prescribed medications. High levels of inflammation in lupus increases your cardiovascular risk. Keeping your lupus under control by regularly seeing your rheumatologist and taking the prescribed medications for your lupus is essential for reducing this risk. If you have high blood pressure or diabetes, it is important that you take any prescribed medications to keep these under control as well.

Q: Are there any special tests I need at my check up?

We recommend screening for high blood pressure. This is done by having your blood pressure checked at your appointments. Blood labs should periodically test for diabetes and your cholesterol levels. Depending on how long you have had lupus, your lupus disease activity, as well as other risk factors for heart disease, your doctor may also consider cardiology consultation and additional testing such as a cardiac stress test. If your rheumatologist has any special concerns about your heart health, you may be referred to a cardiologist, or a specialist at our Cardiovascular Rheumatology Clinic.

Q: Should I be on any additional medications to improve my heart health?

As every lupus patient is different, the choice of medications you should be taking regularly to improve your heart health may be individualized. If you have high levels of cholesterol, you may be started on cholesterol-lowering medications called "statins". Statins improve your cholesterol levels, reduce your risk of heart disease and stroke and are safe and effective in lupus patients. For some patients, your doctor may recommend taking baby aspirin. For patients with hypertension and diabetes, we recommend close monitoring and strict control of your blood pressure and sugar levels. Good control of your lupus with medications other than steroids (prednisone and medrol) is essential because steroids can worsen your blood pressure, cholesterol levels, and diabetes. The most important thing you can do is regularly following up with your rheumatologist and other doctors, taking your prescribed medications, and bringing up any questions or concerns you have at your appointments.

Sarah Chen M.D. is a rheumatology fellow in her 3rd year of training at the BWH Lupus Center. Sarah's research focuses on the quality of care in prevention of cardiovascular disease.

Announcement

Visit our new Lupus Research Program website: **https://lupus.bwh.harvard.edu/** to learn more about our on going research.

To learn more about the Lupus Center and schedule an appointment, visit our website: **http://bit.ly/lupuscenter** or contact us at **617-732-5515**

Have questions or need more information? Corine Sinnette at: **csinnette@bwh.harvard.edu.**

Lupus Patient Assistance Fund

Lupus, because it can be such a complex and difficult disease to manage, often presents a tremendous financial burden for patients and their families. To help aid those affected by lupus, Brigham and Women's Hospital, through the help of generous donors, have established ***The Patient Assistance Support Fund*** for Lupus. This fund looks to help 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 a myriad of forms including subsidized medications, transportation to and from appointments, and aid to patients so they can afford necessary therapies and treatments.

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 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.

LUPUS
RESEARCH
ALLIANCE

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.