



Welcome to the first issue of The Mary Kirkland Center for Lupus Care Newsletter.

At Hospital for Special Surgery, the Mary Kirkland Center for Lupus Care specializes in the treatment of patients with Lupus and Antiphospholipid Syndrome (APS). The recent establishment of the Center in July 2009 marks yet another milestone of extending concerted efforts of reputable minds, compassionate hearts and healing hands to our patients. These newsletters will provide summary updates on ongoing clinical trials and various center programs in the hopes of providing the most superior care and support.

CENTER UPDATES

- ◆ **Free Lupus & Antiphospholipid Syndrome (APS) Classes:** Learn more about clinical manifestations, treatment, research, and the center programs. Sign up for individual, ongoing FREE classes with our center manager. **Please contact Pretima Persad at 646-797-8839 for more information.**
- ◆ **The Cardiovascular Disease (CVD) Prevention Counseling Program** provides FREE cardiovascular disease assessment and education. The CVD program evaluates traditional as well as non-traditional cardiac and lupus-specific risk factors. **Eligibility:** Patients need to be cared for by a Hospital for Special Surgery rheumatologist and carry the diagnosis of lupus and/or antiphospholipid-antibody-positivity. **Please contact Dr. Virginia Haiduc at 212-774-1863 for more information.**

Research Updates:

- ◆ **Lupus News Around the World: Benlysta™ (belimumab)** has the potential to become the first new approved lupus drug in decades for people living with lupus due to two recent clinical trials demonstrating its safe and effective profile. Of note, Hospital for Special Surgery was a participating site for one of these trials. For more information, please visit: www.hss.edu/lupuscenter and click on "Special Reports".
- ◆ **Clinical Trials:** We are looking for new volunteers to participate in ongoing Lupus and APS clinical trials. If interested, Please inquire about studies during your next visit with us or visit www.hss.edu/lupuscenter and click on Research. **You can also contact Pretima Persad at 646-797-8839 for more information.**
- ◆ **Lupus and APS Registry and Repository** is an ongoing collection of data and blood samples from the lupus and APS patients seen at HSS. Over 1040 patients have enrolled since 1995. Enrolling in the Registry takes only 20 minutes of your time. **Please contact Emily Miller at 212-774-2223 for more information.**

Social Work Department Support Programs

- ◆ **SLE Workshop** is a monthly education and support group for all lupus patients and their families.
- ◆ **LupusLine®** is a free national telephone peer counseling service focusing on one-to-one support for people with lupus and their families.
- ◆ **Charla de Lupus (Lupus Chat)®** is a free national peer health education and support program for Spanish-speaking communities with lupus.
- ◆ **LANtern® (Lupus Asian Network)** is a free national support and education program for Asian-Americans with lupus and their families.

Please contact Suzy Kim, LCSW at 212-774-2541 who will be able to provide information and a referral to one of the above programs. You may also visit our web site at www.hss.edu/lupus-programs.

Quick Lupus Facts:

Did you know that lupus comes in different forms?

◆ **Systemic lupus**

erythematosus - affects multiple organs including joints.

◆ **Discoid lupus** - affects only the skin.

◆ **Drug-induced lupus** – a lupus-like picture that develops as a drug reaction.

◆ **Neonatal lupus** - affects newborns and is usually transient.

PATIENT SPOTLIGHT

JESSENIA FILOMENO

Jessenia Filomeno is a 27-year-old patient, diagnosed with lupus at age 8. Learn more from her recent interview with our Lupus Center team.

HSS: *Can you describe your first lupus flare?*

JF: “The flares started as a strong pain on my left arm that ran all the way to the fingertips, legs and back.”

HSS: *Tell us how you came to Hospital for Special Surgery and how you heard about the Lupus Clinic?*

JF: “I used to go to a private clinic in Long Island and their laboratory results were inconclusive. I did not know what I was suffering from. At HSS, I was first referred to a Pediatric Rheumatologist, Dr. Lehman at HSS. As I was transitioning to adult clinic, Dr. Antigone Triantafyllopoulou took

care of me, followed by Dr. Beverly Johnson. All are very knowledgeable doctors who understand my likes, dislikes and concerns.”

HSS: *What is your most touching experience as an HSS patient?*

JF: “I am treated as if I were part of a huge family. From the moment I step in through the entrance, to Nurse Monica’s hugs, to the vast attention from the staff, to Dr. Triantafyllopoulou’s and Dr. Johnson’s specialized care. About three years ago I experienced the most intense flare. I could hardly perform my basic chores. I couldn’t even change my own clothes. However, the symptoms were quickly controlled because of the high quality care I received. Don’t you want to be taken care of by your family whenever you’re sick? Well, Hospital for Special Surgery is my family. This is where I belong.”

HSS: *Can you share a few words about our Lupus Center at Hospital for Special Surgery?*

JF: “For one, HSS provides accurate and advanced laboratory results which confirmed my lupus diagnosis. Also, I am a participant of the Cardiovascular Disease Prevention Counseling Program that is simply great! I just attended their patient seminar. We watched the American Heart Association’s video with a question and answer portion that really made learning fun. Now I have much better control of lupus because of HSS’ help. I am also assigned to a nutritionist, Sotiria Tzakas, who recommends which healthy foods are best for me.”

HSS: *What would you recommend to other lupus patients?*

JF: “Get support from your family. Work with your doctors, especially Hospital for Special Surgery doctors as they know what is best for you. Most importantly, you need to discipline yourself. Don’t let lupus control you, you have to control it.”

NOTE FROM OUR DIRECTORS

This first issue of the newsletter serves as an introduction to the many services that the Lupus Center provides. It is important that all HSS patients feel as if they are part of a lupus family under the umbrella of our Center – and that is the atmosphere that the staff of the Lupus Center aim to provide. We hope that you will take advantage of the services mentioned in this newsletter.”

Dr. Doruk Erkan & Dr. Kyriakos Kirou
Clinical Co-Directors
Mary Kirkland Center for Lupus Care

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