The Need for Diversity in Lupus Research

**Why do Asian lupus patients develop severe kidney disease, called nephritis, at a higher rate than non-Asian patients?**

**Why is lupus three times more common in African American women than Caucasian women?**

Lupus (SLE) has long been recognized as one of the most complex autoimmune diseases with the potential to affect multiple organs. Of equal challenge to doctors and researchers is understanding how and why SLE can vary so greatly in risk and severity depending on a patient’s ethnicity. While environmental factors, such as infections and stress account for 35 percent of the risk of developing SLE, genes contribute 65 percent. Genes may very well hold the clues as to why certain populations are more significantly impacted by SLE.

**Who has SLE**

According to the Centers for Disease Control (CDC) Office of Minority Health, SLE is three times more common in African American women than in Caucasian women, and is also more common in women of Hispanic, Asian, and Native American descent. Dr. Lindsey Criswell and her team are working hard to make the Lupus Genetics Research Project representative of the groups affected in the general population. Criswell points out that, “For those groups to benefit maximally from new discoveries and new therapies that follow from that, they need to be represented in the research to be sure that the results are going to be relevant to them.”

**How identifying the genes associated with SLE will help patients**

Once doctors understand the role genes play in disease development, patients will benefit from better diagnostic and prognostic tools. That means doctors will be able to make a more specific diagnosis at an earlier stage of the disease and, once the diagnosis is made, patients will learn what their course is likely to be so that they can be monitored more frequently. “Any genes that play a role in the disease are logical targets for therapies,” Criswell notes, adding “Most of our current therapies are still non-specific, that is they don’t target specific proteins or genes.”

**How you can help**

If you know someone who has SLE, especially someone of African American, Asian or Hispanic heritage, please encourage them to take part. As a study participant you can let them know how easy it is to enroll - the entire process can be done from home! We simply need completion of a questionnaire and consent forms and a DNA (saliva and/or blood) sample.

Please ask anyone who is interested to contact us at toll free (888) 223-3067 x1.
New Genetic Predictor for Pneumonia in Lupus Patients

Pneumonia is the most common lung disease in patients with lupus (SLE), responsible for a significant proportion of hospitalizations and deaths. There are several known reasons why SLE patients develop pneumonia at such a high rate including, low white blood cell counts and immune system suppression from the medications used to treat SLE. These clinical factors, however, do not fully explain why SLE patients have such a high rate of pneumonia and other infections.

University of California San Francisco (UCSF) research fellow Dr. Brent Kinder, working under the guidance of Dr. Lindsey Criswell, studied the medical histories and genetic typing of 282 SLE patients in order to determine whether certain genetic risk factors increased the risk of pneumonia. Of that group 65 patients (23 percent) had at least one episode of pneumonia; 10 had multiple episodes. The results indicated that patients who had a specific combination of genetic markers within the TNF-alpha gene had a 4-fold increased risk of developing pneumonia.

The TNF-alpha gene is a strong new predictor for pneumonia in SLE patients. Identification of genetic risk factors may lead the way to ultimately avoiding pneumonia in SLE patients through preventive measures and immunization.

“These results add to the growing body of knowledge to inform the genetically tailored management of individual patients.”

Genetics Research Projects Under Way

Anyone with a diagnosis of lupus (SLE) or rheumatoid arthritis (RA) is invited to take part in the Lupus and Rheumatoid Arthritis Genetics Research Projects. Once you are enrolled, you may be eligible to participate in additional studies:

1) Mother-Child Study: Pregnancy and autoimmune disease
2) Lupus Outcomes Study: Tracking patients over time
3) Living With Lupus Study: Exploring women’s health and well-being

To learn more about or to enroll in the Lupus or Rheumatoid Arthritis Genetics Research Projects, call toll free (888) 223-3067 x1.

Family Ties in Rheumatoid Arthritis

Sisters of Affected Males Have Increased Risk of Developing Severe RA

With the understanding that males appear to require an increased “load” of genetic risk factors to develop rheumatoid arthritis (RA), a recent study of 1,004 individuals with the disease confirmed that the presence of an affected male sibling in a family influences the expression of disease among female siblings. Specifically, female RA patients who have brothers with RA had a higher frequency of RA-related autoantibodies than female RA patients without affected brothers.

Dr. Lindsey Criswell, the study’s senior author, notes that “We now understand that patients with these autoantibodies are at greater risk of having destructive arthritis and severe RA generally.” She adds that, “These findings underscore the value of family history information since women with RA, or with early symptoms suggesting RA, are more likely to develop severe disease requiring earlier and more aggressive treatment if they have male relatives with the disease.”

The patients studied are part of the North American Rheumatoid Arthritis Consortium (NARAC) which was established to create a resource for RA gene mapping studies.
**Give a Little Bit**

Why is blood so important to us? Why don’t cheek cells and saliva satisfy our quest for DNA? The blood is simply more valuable to us in terms of the amount of research we can perform. A blood sample provides 75 times more DNA than a cheek cell (buccal) sample.

We want to make it as easy as possible on patients and their families. Here’s how you can provide a blood sample from anywhere in the country:

- **We can mail a blood kit directly to your home.** Simply take the FED EX envelope containing the kit to your physician’s office or local lab at your earliest convenience. The lab will bill us directly for the blood draw — there is NO CHARGE to you. Your sample is shipped to us by the lab and, upon receipt, we mail a check to you for $25.

  **OR**

- **Visit us at UC San Francisco to have your blood drawn.**
  The appointment takes approximately 30 minutes. We’ll pay for your parking and reimburse you $25 for your time.

How much do we want? Two tablespoons does the trick. That’s all!

Your samples fuel our research and we are grateful for your contributions.

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**New Saliva Collection Method**

We are now using saliva collection kits to collect DNA samples from new participants and anyone who provided a buccal brushing in previous years.

Please do not eat or drink 1 hour before providing the sample. Bits of food and beverages will degrade the quality of your DNA. We provide chewing wax and sugar to help increase saliva production.

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**Keep In Touch!**

We want to be able to share future research updates and important news with you about the studies you and your family members are enrolled in. Please let us know if:

- You have moved
- You need a replacement DNA collection kit or forms
- You are willing to donate a blood sample
- Additional family members have developed an autoimmune disease

Thank you for your participation in this important research!

Call us toll free at (888) 223-3067.
Or visit our website:
http://medicine.ucsf.edu/lupus

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**Lupus Outcomes Study Update**

**Tracking Patients Over Time**

The Lupus Outcomes Study (LOS) is a long-term study of participants in the UCSF Lupus Genetics Project, designed to collect information about how people with SLE cope with their illness, and the medical and social factors that predict positive health outcomes for these individuals. The study began in 2002, and we are currently conducting our 4th annual interview wave. Thanks to the dedication of the LOS panel members, we have been able to re-interview over 90 percent of eligible participants each year — an amazing feat! To those of you who are part of the study, we want to again express our appreciation for your willingness to give your time to this endeavor. The faculty and staff involved with the study have been hard at work analyzing the results of the first three interviews. We will send out another research update soon.

In the near future, we will begin an exciting new study as part of the LOS, looking at how body composition (the amount of fat and muscle in the body) affects functioning in people with lupus. LOS members who take part in this study will be asked to come to UCSF for a study visit twice over three years. Through this study, we hope to identify people with lupus who are most likely to develop problems with functioning and things that may help people avoid those problems. Those of you who live within driving distance of UCSF will hear more about this new study from the interviewers in the coming months.
Other Research Efforts

Scientific Advances Bring Increased Hope for Improved Therapies to Treat Lupus

Lupus (SLE) patients and physicians from UC San Francisco, Stanford, Kaiser Permanente and private practices across Northern California have joined together to form LERN: Lupus Erythematosus Research Network with the goal of finding effective new treatments for SLE. Patients who choose to join LERN will be kept informed of the latest clinical studies focusing on the disease. To learn more about LERN and ongoing clinical trials, visit the UCSF SLE website at http://medicine.ucsf.edu/rheum/lupus or contact the UCSF clinical trials center at (415) 502-1886.

Brain Imaging and Cognitive Functioning in Lupus

Many lupus (SLE) patients notice changes in their mood and/or thinking skills (e.g., memory, concentration). Dr. Laura Julian is conducting research to better understand the relationship among these symptoms and SLE disease processes. For more information, contact Dr. Laura Julian at (415) 502-4587.

UCSF Autoimmune Disease Genetics Research Projects
Funded by:

Mary Kirkland Center for Lupus Research

University of California
San Francisco

3294
UCSF Autoimmune Disease Genetics Research Projects
San Francisco, CA 94143-0500

Address Service Requested

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