



RESEARCH STUDY FINDS HIGHER NUMBERS OF PEOPLE WITH LUPUS

Increased Burden on Black Women

(November 8, 2011, Washington, DC) In an abstract being presented today during the American College of Rheumatology Annual Scientific Meeting in Chicago, Dr. S. Sam Lim of Emory University School of Medicine will present data showing that black women have a significantly higher incidence of systemic lupus erythematosus than most reports in the scientific literature. The data, gathered through the Georgia Lupus Registry that is funded by the Centers for Disease Control and Prevention (CDC), also indicates that overall prevalence of lupus in this population is higher than seen in previous studies, suggesting longer survival and/or more frequent diagnosis of lupus. According to Dr. Lim, lupus continues to affect significant numbers of people across racial and ethnic lines, but with a disproportionate burden on black women.

The Georgia Lupus Registry was designed to more accurately estimate the incidence and prevalence of lupus for blacks and whites in the two counties in and around the city of Atlanta, and is one of five U.S. population-based registries funded through the CDC. The [Lupus Foundation of America](#) (LFA) successfully advocated Congress to appropriate \$18.4 million to support population-based registries as part of a broader national epidemiological study to understand the full impact of lupus on individuals and families. The registries are gathering data on various racial and ethnic groups to obtain a more accurate picture of how lupus affects all populations.

“This study represents the first step of a long and complicated process required to obtain a clear picture of lupus and its impact,” said Sandra C. Raymond, President and Chief Executive Office of the Lupus Foundation of America. “The data from this study are only one piece of a much larger puzzle. Additional information is needed for all forms of lupus and all groups believed to be at high risk for the disease, including Native Americans, Hispanics, and Asians. Studies on these populations have just been initiated and will not be completed for several years.”

“Estimates for the number of people affected by lupus are outdated and have varied widely due to the use of different case definitions, limited sources for case ascertainment, and small source populations,” said Dr. Lim. “This study is needed to better understand and measure the burden of the illness and the social and economic impacts of the disease, and to stimulate additional private investment by industry in the development of new, safe, and effective therapies for lupus.”

In the Georgia study, trained investigators surveyed medical records to identify cases of lupus that were being treated in hospitals and by rheumatologists, nephrologists, and dermatologists. The reports from this initial analysis, however, only included cases of lupus that met rigid criteria established by the

American College of Rheumatology (ACR) to ensure uniformity of data in research. Not included in the data are cases that were managed by other medical specialists or general practice physicians, mild cases where the individual is not undergoing medical care, or undiagnosed cases. However, results from the Georgia Lupus Registry study provide additional and more accurate evidence that lupus is a significant and complex disease that requires a long and difficult process to diagnose due to vague symptoms and an unclear pattern of disease activity.

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