LUPUS: A SIGNIFICANT PUBLIC HEALTH ISSUE FOR THE AFRICAN AMERICAN COMMUNITY

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Lupus strikes without warning, affects each person differently, and has no known causes or cure. It is a chronic autoimmune disease in which the immune system becomes imbalanced and fails to distinguish between viruses, bacteria, and healthy tissues and organs. An estimated 1.5 million people in the United States suffer from the disease.

Lupus among racial and ethnic minority groups is a dramatic and significant public health problem that cries out for national attention and resources. Ninety percent of all people affected by lupus are women—although men and young children also develop the disease—and African Americans are three to four times more likely to develop lupus. The lupus spectrum encompasses various forms of the disease, such as drug-induced lupus, neonatal lupus, and systemic lupus erythematosus (SLE), which can impact any organ or tissue in the body, including the kidneys, joints, heart, brain, and blood system and skin. People with lupus can experience significant symptoms, such as pain, extreme fatigue, hair loss, cognitive issues, and physical impairments that affect every facet of their lives. Many suffer from cardiovascular disease, strokes, disfiguring rashes, and painful joints. For others, there may be no visible symptoms. The root causes of lupus are not known and there is no cure. However, scientists believe there are three factors that can lead to the development of lupus, including genetics, environmental triggers, and hormonal influences.

There is no question that lupus disproportionately affects women of color and that morbidity and mortality are observed to be at much higher rates in those populations. Recent studies indicate that lupus affects 1 in 537 young African American women. The LUMINA (Lupus in Minority Populations: Nature vs. Nurture) study/report states that “African American lupus patients are more likely to have organ system involvement, more active disease, higher frequency of auto-antibodies, lower levels of social support, and more abnormal illness related behaviors compared with White lupus patients.” Other studies have demonstrated that minority women tend to develop lupus at a younger age, experience more serious complications, and have higher mortality rates—up to three times the incidence of mortality than that of Caucasians. Outcomes for lupus nephritis—lupus that affects the kidneys—are worse for minority populations compared to Caucasian lupus patients. Additionally, non-White patients are more likely to suffer from lupus-related depression, cardiovascular disease, and diabetes, and have worse health-related quality of life than White patients.² While the root causes of these disparities are not well understood, studies looking at this problem have found that people of lower socioeconomic status have higher rates of incidence, severity, and mortality from lupus than people with higher socioeconomic status.

WHAT IS CURRENTLY BEING DONE

In recent years, there has been an erosion of funding at the National Institutes of Health and other vital agencies—such as the US Food and Drug Administration’s (FDA) approval of safe and effective treatments for patients. Without adequate and robust funding for biomedical research, progress into discovering, developing, and delivering new medications to people with lupus will continue to be delayed. The result will have a devastating impact on all people with lupus, especially members of the African American community who are at greatest risk for the disease.

RESEARCH

Findings from the Hopkins Lupus Cohort, a longitudinal study that has followed patients with lupus through quarterly (or more frequent) visits since 1987, highlighted the factors that contribute to a lack of health equity in lupus. They include education level, adherence to medical advice and medications, social support, medical insurance, access to care, and geographic area of residence. This research suggests that there is an urgent need to focus on healthcare access, education about lupus, and in-
increased awareness and adherence to therapies prescribed by physicians.

In recent years, the United States Centers for Disease Control and Prevention (CDC), has been conducting an epidemiological study to determine the prevalence and incidence of lupus at five sites across the United States, including:

1. Atlanta, Georgia
2. New York City, New York
3. Detroit, Michigan
4. San Francisco, California
5. Indian Health Service based in Alaska

Preliminary findings indicate that the prevalence of lupus is higher than previously thought, but data from all sites have not yet been analyzed. Generally, the study found that Black women living with lupus were diagnosed at a younger age compared to White women, and had a higher proportion of renal disease and end-stage renal disease. In particular, the Michigan and Georgia investigators found substantial evidence that African Americans are affected by lupus at a greater rate and more severely than other populations.

The investigators plan to use their lupus patient registries to conduct ongoing studies to document the progression of the disease and the economic burden of lupus over time, which, according to data analysis already available, is substantial. (Of note: Other research has shown that the costs associated with lupus nephritis can top $65,000 per patient per year). Through improved management of the disease, people with lupus now have increased survival rates, but many will face a lifetime of serious health problems that will require expensive medical care, citing the need for increased investment in lupus research and development of new and more targeted therapies to bring the disease under control and improve quality of life.

NEEDS ASSESSMENT

There is evidence-based research that can inform the development of proactive initiatives to address this significant public health problem.

The Lupus Foundation of America is committed to identifying ways to streamline and strengthen the link between research and practice by focusing on the determinants of lupus disparities among African Americans, testing and evaluating community-based interventions to increase health equity, and working with a broad base of collaborators to help achieve positive results.

Past studies have helped us understand that disparities exist with regard to the incidence and prevalence of lupus, but they have not given us the kind of baseline information we need to know about medical care, access to care, and other important health needs for those living with the disease. The Lupus Foundation of America is currently conducting a study to determine why it takes an average of six years for someone with lupus to receive an accurate diagnosis. Additionally, the study will look at the services individuals need once diagnosed, including an understanding of the issues related to access to quality and affordable health care.

AWARENESS CAMPAIGNS

The “Could I have Lupus” campaign, designed by the Ad Council, launched in March 2009 with a goal to increase awareness of lupus among young minority women of childbearing age (18 to 44 years) and to educate them on how to identify early warning signs of lupus in hopes of increasing the likelihood of early diagnosis. The Lupus Foundation of America was the founding partner on the campaign. The campaign was a $2,393,103 investment. With over $70 million received in donated media support, the total return on investment was over 2,800 percent, meaning that for every dollar invested, the campaign received $28 in donated media support. Campaign results include:

- The percentage of women reporting that they had recently seen or heard about lupus increased significantly, from en percent in 2009 to 15 percent in 2010.
- More women reported visiting a website to get information about lupus, increasing from nine percent in 2009 to 14 percent in 2010.
- Among women reporting multiple symptoms of lupus identified from a list of common symptoms, five percent said they had already spoken with a doctor about a lupus evaluation, a small but significant increase from 2009 (two percent).

Recently, the Lupus Foundation of America launched the KNOW LUPUS awareness campaign to combat the fact that nearly two-thirds of the general public knows little or nothing about lupus. The campaign features a series of television public service an-
nouncements, which includes testimonials and statements from people with lupus and celebrity advocates. The centerpiece of the campaign is an online, animated, and interactive game to test people's knowledge of lupus and drive support for lupus research. While the campaign is still in its beginning phase, long-term goals include increased awareness and knowledge of lupus in order to improve health equity for all who suffer from lupus.

PATIENT & PROVIDER EDUCATION

Greater physician and patient education could increase health equity in lupus patients. Those most likely to be sick are also more likely to be uninsured and less likely to have access to the care they need, according to The Lupus Initiative, a multi-faceted education program championed by the Lupus Foundation of America and centered on increasing medical professionals' understanding and awareness of lupus. The Lupus Initiative, funded by the U.S. Department of Health and Human Services, Office of Minority Health, provides comprehensive educational resources to physicians, educators, students and other medical professionals to help them diagnose, treat and manage lupus in patient populations disproportionately affected based on race, ethnicity, and gender. The more a medical professional knows about lupus, the more likely he or she is to identify its signs and symptoms early and accurately to diagnose the disease or refer a patient to a specialist.

THERE IS SO MUCH TO BE DONE

March 9, 2011, marked an important landmark for the lupus community. The FDA announced approval of the first drug ever designed specifically for the treatment of lupus and the first drug approved for lupus in over 50 years. But one drug will never be enough to treat lupus, which impacts every person differently. The fact remains that we need a robust and expanded biomedical research effort on lupus, and we need an arsenal of safe and effective lupus treatments. Additionally, we must conduct research to truly understand specific physical, social, emotional, and other challenges that can be overwhelming for medically underserved, minority populations. Past efforts have not yet succeeded in creating greater health equity, in part, because they may be based on generalities and not actual social, emotional, and medical needs. But some studies suggest that it would be important to develop teams of experienced physicians, educators, and caregivers working with patients and their loved ones to strengthen social support, enhance self-efficacy, and decrease co-morbidities such as smoking, hypertension, and obesity.

CLINICAL TRIALS

Treating the vast and varying symptoms of lupus is challenging. Developing therapies directed at the disease itself has proven even more difficult. The drug development landscape for lupus has changed for the better over the years with more than 30 compounds in development for lupus, and the demand for patient participation in clinical trials is extremely high. Lupus is a model disease for heterogeneity and disproportionate burden on minority communities, where traditionally participation in clinical trials has been lacking.

There must be a focused effort on developing and implementing a clinical trial education action plan for lupus to increase participation in minority populations that are disparately affected by lupus and who are historically underrepresented in clinical trials.

Recommendations on how to achieve positive results include:

- Creating culturally appropriate and sensitive educational materials about the benefits of participation in a clinical trial
- Developing strong local and community leaders to create trust and promote participation in clinical trials and research
- Promoting the need and understanding to engage in clinical trials; use effective culturally appropriate recruitment mechanisms to improve the connection of people with lupus with clinical trials and academic sponsors
- Supporting new and innovative clinical trial designs across clinical and sociodemographic subpopulations to facilitate drug discovery in lupus and identify new targets for drug development

NATIONAL PUBLIC HEALTH AGENDA FOR LUPUS

Recently, the CDC, the National Association of Chronic Disease Directors (NACDD), and the Lupus Foundation of America collaborated to develop the first-ever National Public Health Agenda for Lupus. The first-ever Public Health Agenda for Lupus will provide a broad public health approach to lupus diagnosis, disease management, treatment and research, and serves
as an overall blueprint for action in lupus to help guide future policy, planning, advocacy, and action initiatives. Organized and framed under the CDC Four Domains of Chronic Disease Prevention that include epidemiology and surveillance, environmental approaches, health care system interventions, and community programs linked to clinical services, the Agenda also specifically addresses health disparities.

While the final report will be available in Fall 2015, a number of recommendations focused on improving health equity include: expanding the studies of incidence and prevalence of lupus among racial and ethnic minorities and examining disparities in quality of life and care through additional cohort studies; leveraging collaborations among community and faith–based organizations to promote community-based self-management services; and, developing comprehensive awareness campaigns with targeted messages to ensure timely diagnosis and proper treatments.

CONCLUSION

The significance of lupus in the African American community can no longer be ignored, and it is clear there is much work to do in improving health equity among those who suffer from this disease. The anchor for improving health equity begins with a robust medical research effort that will uncover the causes of lupus leading to new, effective, and tolerable treatments that can improve the quality of life for all people with lupus. In addition to funding a robust biomedical, clinical, and public health research effort in lupus, together we must work to ensure patients and physicians are educated about lupus to help reduce the time to disease diagnosis, ensure patients are starting the correct treatments faster in order to limit organ damage, and ensure patients are connected with valuable and culturally appropriate supports and services to help manage living with this cruel and mysterious disease.

