

# LUPUS

## THE FACTS, THE CHALLENGE, AND THE PROMISE OF RESEARCH

### LUPUS TODAY

- Systemic lupus erythematosus (SLE, or lupus) is a chronic, potentially devastating autoimmune disease in which the immune system turns against the body's own cells and tissues, causing inflammation and tissue damage. Lupus can affect many parts of the body, including the joints, skin, kidneys, heart, lungs, blood vessels, and brain.
- Lupus affects people of all ages, including children, but it most often strikes people when they are between the ages of 15 and 45. Nine out of ten people with lupus are women. Source: National Institutes of Health
- Lupus is three times more common among African American women than among Caucasian women, and is also more common in women of Hispanic, Asian, and Native American descent. Source: National Institutes of Health

**Lupus is by far the leading cause of death among young women with autoimmune diseases.**

- The risk of heart attacks, stroke, kidney failure, and osteoporosis is much higher in people with lupus than in the general population.
- The number of people with lupus in the U.S. has been estimated to range from at least 270,000 to more than one million. It is difficult to estimate how many people have lupus because its symptoms vary widely and can come and go, its onset is hard to pinpoint, and diagnosis can be elusive.
- The exact cause of lupus is unknown. Research suggests it is caused by a combination of genetic factors that make a person susceptible to the disease and environmental factors such as infection, sunlight, or stress that trigger the disease in susceptible individuals.

### THE COST OF LUPUS

The best available data indicate that the average annual cost of lupus resulting from medical expenses and lost productivity is at least \$26,900 per person.\* This translates to an annual cost to the U.S. economy of at least \$7.3 billion.\*\* The cost of lupus in terms of reduced quality of life is unknown.

\*Sources: G Gironimi et al. 1996. *Arthritis & Rheumatism* 39: 979-987.  
AE Clarke et al. 2000. *Journal of Rheumatology* 27: 2597-2604.  
Costs translated to 2002 U.S. dollars.

\*\*Based on the conservative estimate of 270,000 people with SLE in the U.S.

### THE CHALLENGE

- There is no known cure for lupus, and the same small group of medications—mainly corticosteroids and chemotherapy drugs—has been used to treat lupus for decades. These drugs are toxic, have unpleasant and sometimes-serious side effects, and can cause a host of long-term complications including osteoporosis, diabetes, infertility, and severe infections. Developing new, more targeted treatments that are safer and more effective is a high priority.
- No single test can determine whether someone has SLE, and it may take several years after symptoms first develop before doctors can make a definitive diagnosis. *...continued*

### *Living with Lupus*

*Name:* Gena Carter, MD  
*Age:* 45



Dr. Gena Carter was diagnosed with SLE in March of 1999, at age 41, after she began experiencing extreme fatigue and an intense burning sensation in her hair follicles, followed by hair loss. Her first debilitating disease flare, in March 2000, was marked by vision problems, facial paralysis, joint pain, and “indescribable fatigue,” and resulted in the first of several hospitalizations. Lupus has affected many parts of Gena’s body, causing gastrointestinal ulcers, infertility, joint pain, skin rashes, neurological problems, and uterine bleeding from inflamed blood vessels.

After she was diagnosed with lupus, Gena, a radiologist who describes herself as “a passionate provider of breast cancer imaging and diagnosis,” tried to maintain her usual active schedule. But the disease has restricted her to a 10-hour workweek and keeps her from doing everything she would like to do. “I now plan my life moment by moment, which is very difficult for me,” she says. Gena is sustained by excellent medical care at Boston’s Faulkner Hospital along with her deep faith and the help of friends and family members. To keep her symptoms under control, she often has to take high doses of steroids. “I do not have self-pity,” she says. “I just wish there could be a cure, and I wait expectantly for that.” In the meantime, Gena—like many people living with lupus—hopes to benefit from efforts to develop new, less toxic medications that are specific for the disease. And to make better treatments and a cure a reality, she says, “research is the only way.”

## THE CHALLENGE *continued...*

- Although survival rates have improved dramatically since the 1950s, death rates for people with lupus are still three to five times higher than in the general population.
- Between 1979 and 1998, death rates from lupus increased by about 70 percent among African American women aged 45–64 years. Source: JJ Sacks et al. 2002. Morbidity and Mortality Weekly Report 51: 371-374.

## THE PROMISE OF RESEARCH

Researchers are beginning to gain insights into the underlying causes of lupus and identify potential targets for new treatments. Yet many mysteries about lupus remain to be solved, and more research is needed to speed development of better treatments and find a cure.

The Alliance for Lupus Research (ALR), a nonprofit organization, is making a significant contribution toward achieving these goals through its support of innovative research in top laboratories around the world. Founded in 1999, the ALR applies a strategic business approach to its mission to prevent, treat, and cure lupus through medical research. By providing large grants in areas identified as most likely to lead to a cure, the ALR is helping to accelerate the pace of lupus research.

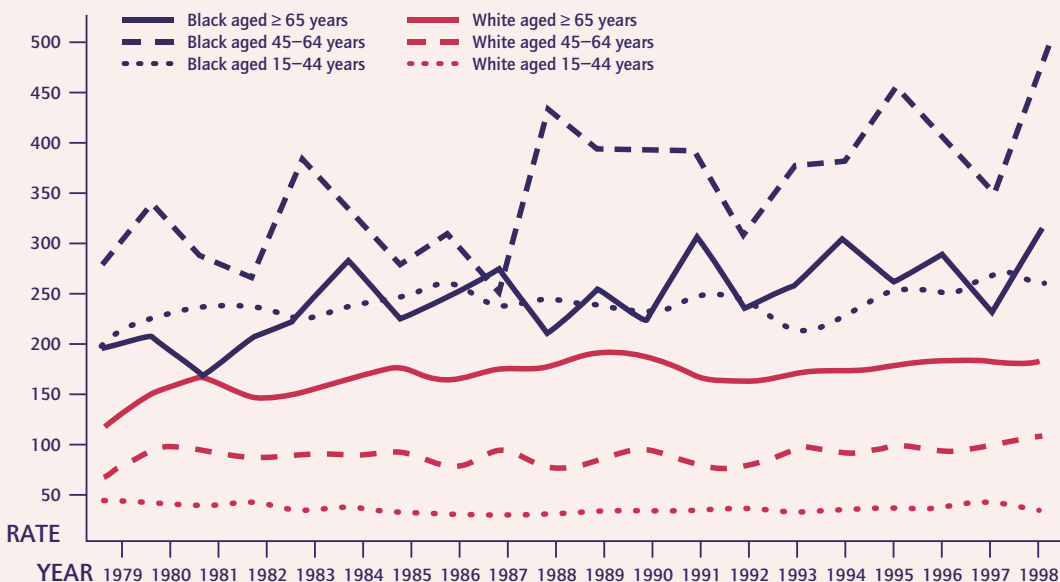
## HOPE FOR THE FUTURE

Intensified efforts in lupus research by organizations such as the ALR as well as the federal government and private industry, together with recent advances in understanding the disease, provide new hope that better treatments, and, ultimately, a cure for lupus will become a reality.

## EXAMPLES OF PROGRESS MADE BY ALR-FUNDED INVESTIGATORS

- Novel insights on the causes of pregnancy loss in an animal model of lupus that have opened the door to human studies and may lead to safer, more effective ways of preventing recurrent miscarriages in women with SLE.
- The identification of distinctive patterns of gene activity in blood samples from lupus patients, which could lead to more accurate diagnostic tests and provide better ways to monitor and predict changes in disease activity.
- Findings supporting the growing body of evidence that interferon-alpha, a protein that has potent effects on the immune system, plays a critical role in lupus. The ALR has taken the lead in this area of research, which includes the development of potential therapies that block the actions of interferon-alpha.
- Identification of new approaches for targeting white blood cells known as B cells and blocking their destructive actions in people with lupus. Ongoing studies are building on these findings to develop potential therapies that would selectively eliminate disease-causing B cells without harming normal, infection-fighting B cells.

## SYSTEMIC LUPUS ERYTHEMATOSUS DEATH RATES\* AMONG FEMALES, BY AGE GROUP AND RACE United States, 1979–1998



\*Per 10 million population.

Source: U.S. Centers for Disease Control and Prevention



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PREVENT. TREAT. CURE.

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