## Lupus—a Particular Health Problem for African Americans

In lupus, the immune system, which is designed to protect against infection, creates antibodies that attack the body's own tissues and organs – the kidneys, brain, heart, lungs, blood, skin, and joints.

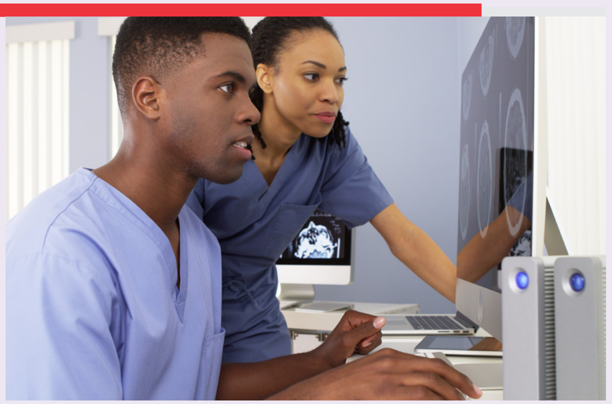
More than 90% of people with lupus are women. Most commonly, lupus first strikes between the ages of 15 to 44.

African American women are 3-4 times more likely to develop lupus than Caucasian women.

Of any race, African Americans develop lupus at a younger age and have worse symptoms. African Americans with lupus are 3+ times more likely to die than Caucasians.

## Lupus Needs More Treatments

There is no known cure for lupus. Few medications are approved for treating lupus, and only one was developed specifically for the disease. But all drugs must be tested in clinical trials to be approved by the U.S. Food and Drug Administration as treatments for lupus. And volunteers that represent every potential patient group are critically important.



## Smart Questions to Ask About Participating in a Clinical Trial

- How long will I be in the study?
- Can I keep taking my other medicines?
- How often will I have checkups, have to give blood, or undergo other tests?
- How will participation affect my ability to work, go to school, take care of my kids?
- Will I need someone to drive me to doctors' appointments and lab tests?
- Will this affect my ability to have children some day?
- Can I keep seeing my regular rheumatologist and other doctors?
- Will I get reimbursed for travel and/or childcare costs?
- Will I find out the results of the trial I was in?
- Can I take the experimental medicine after I complete the trial?

*For more information on lupus clinical trials visit*
**LupusResearch.org/trials**

LUPUS
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**The Lupus Research Alliance** is transforming the lives of people affected by lupus through the power of science to drive new treatments, prevent disease progression, and find a cure.

100% of all donations goes to support lupus research programs because the Lupus Research Alliance Board of Directors funds all administrative and fundraising costs.

**Lupus Research Alliance**
275 Madison Avenue, Floor 10
New York, NY 10016

212-218-2840
lupusresearch.org

# AFRICAN AMERICANS AND LUPUS

## The **hope** of clinical trials

African American women are at greatest risk for developing lupus and worse disease symptoms.

But African Americans are under-represented in studies testing new treatments.

LEARN HOW YOU CAN HELP ▶

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> *"I am taking part in a trial because my doctor and I felt it was the best treatment option for me. I know I am getting excellent treatment with people who really care. Taking part in a trial is very empowering. I feel it is especially important for people of color to participate in trials because we are under-represented in most studies. If we're not represented in trials, researchers have no way of knowing if the drugs tested will be safe and effective for us."*
>
> - Kaamilah Gilyard, Lupus Patient & Advocate

### WHAT IS A CLINICAL TRIAL?

Clinical trials help to answer the question, "Will this drug help people and is it safe?"

In clinical trials, people volunteer to test new treatments, interventions or tests, so researchers can determine what does and doesn't work. Clinical trials also help researchers and doctors decide if the benefits outweigh possible side effects. They can also provide another treatment option.

*Learn more about clinical trials at*
**LupusResearch.org/trials**

## Why Participate in a Clinical Trial?

### POSSIBLE BENEFITS

For some people, enrolling in a clinical trial may be the chance to get state-of-the-art treatment and specialized medical attention. Some trials even pay for travel costs, or other trial-related expenses.

For others, participation may be a chance to try new medicines and learn more about the disease. Some patients feel a personal satisfaction of helping find answers for today's patients and future generations.

### POSSIBLE RISKS

The medicine being tested may not work. Side effects may be serious or unpleasant.

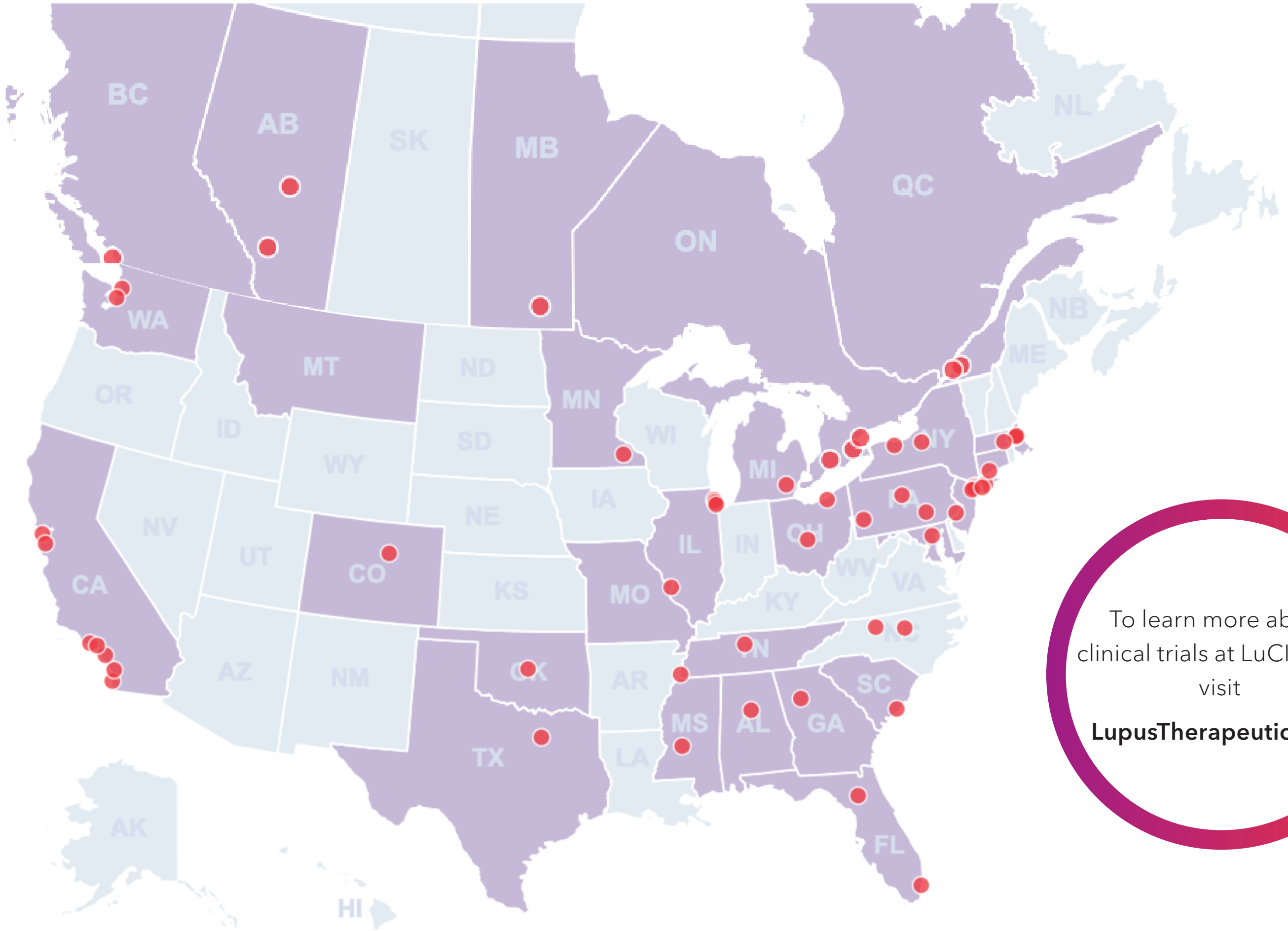
A health professional must explain the possible risks and side effects during the informed consent process.

## Why African Americans are Needed for Clinical Trials

African Americans make up 13% of the U.S. population but are under-represented in many clinical trials testing potential treatments. Only 5% of all trial participants are African American.

Medicines can affect people differently and must be tested among each potential patient group–by race, gender, age, and ethnic background– so doctors can know how to use them safely and effectively.

This is especially important for African Americans, who are underrepresented in clinical trials.



To learn more about clinical trials at LuCIN sites visit

**LupusTherapeutics.org**

## Lupus Clinical Investigators Network Sites

The Lupus Research Alliance formed the Lupus Clinical Investigators Network (LuCIN) to accelerate the identification and development of new therapies for treating lupus. LuCIN is made up of leading lupus experts at top research centers throughout the U.S. and Canada. Several promising studies are underway through LuCIN. It is administered by Lupus Therapeutics, an affiliate of Lupus Research Alliance.

*Learn more about LuCIN at* **LupusTherapeutics.org**

ALABAMA
University of Alabama at Birmingham

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Stanford University
University of California – Irvine
University of California – Los Angeles
University of California – San Diego
University of California – San Francisco
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COLORADO
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Emory University

ILLINOIS
Northwestern University
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University of Maryland School of Medicine

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Oklahoma Medical Research Foundation

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Penn State University/Hershey Medical Center
Temple University
University of Pennsylvania
University of Pittsburgh

SOUTH CAROLINA
Medical University of South Carolina

TENNESSEE
University of Tennessee Health Science Center
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TEXAS
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*As of April 2019*

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