

## 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.

Lupus research has been greatly advanced by the caring people who participate in clinical trials. In these studies, scientists and participants work together to find safer, more effective ways to diagnose, prevent, and ultimately cure lupus.



*"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

## about the Lupus Research Alliance

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.

Because the Board of Directors funds all Lupus Research Alliance administrative and fundraising costs, 100% of all other donations go directly to support research programs.

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

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



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[lupusresearch.org](http://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



**LUPUS**  
RESEARCH  
ALLIANCE

## 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. Five treatments are commonly used, 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.

LEARN HOW YOU CAN HELP

VISIT: [LupusTrials.org](http://LupusTrials.org)

## 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 in a trial may be a chance to try new medicines, learn more about the disease, and have the personal satisfaction of helping science find answers.

### 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 safely and effectively.

It is especially important for African Americans, who tend to have more severe complications, to participate in trials so potential lupus treatments can be tested.



VISIT [LuCIN.org](http://LuCIN.org)

## Lupus Clinical Investigators Network Sites

The Lupus Research Alliance launched 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.

### Alabama

University of Alabama at Birmingham

### California

Stanford University

University of California – Irvine

University of California – Los Angeles

University of California – San Diego

University of California – San Francisco

University of Southern California

Wallace Rheumatic Studies Center

### Colorado

University of Colorado

### Connecticut

Yale School of Medicine

### Florida

University of Florida

University of Miami

### Georgia

Emory University

### Illinois

Northwestern University

Rush University Medical Center

University of Chicago

### Maryland

University of Maryland School of Medicine

### Massachusetts

Beth Israel Deaconess Medical Center

Brigham and Women's Hospital

Massachusetts General Hospital

University of Massachusetts – Worcester

### Michigan

University of Michigan

### Minnesota

Mayo Clinic

### Mississippi

University of Mississippi

### Missouri

Washington University School of Medicine

### New York

Albert Einstein College of Medicine

Columbia University Medical Center

Feinstein Institute for Medical Research

New York University

Northwell Health

State University of New York – Syracuse

The Hospital for Special Surgery

University of Rochester

### North Carolina

University of North Carolina at Chapel Hill

Wake Forest University School of Medicine

### Ohio

Case Western Reserve University – MetroHealth Medical Center

The Ohio State University

### Oklahoma

Oklahoma Medical Research Foundation

### Pennsylvania

Allegheny General Hospital

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

Vanderbilt University

### Texas

University of Texas – Southwestern

### Washington

University of Washington

Virginia Mason/Benaroya Research Institute

### Canada

Arthritis Research Canada

McGill University

McMaster University

The University of Alberta

The University of Calgary

The University of Western Ontario

Université Laval - Québec

University of Manitoba

University of Toronto

University of Vancouver