

FACTS ABOUT LUPUS:

Lupus is one of the cruelest, most mysterious diseases on earth—an unpredictable and misunderstood autoimmune disease that ravages different parts of the body. It is difficult to diagnose, hard to live with, and a challenge to treat.

Lupus Facts

- Lupus is a complex disease that is hard to define. It strikes without warning, affects each person differently, and has no known causes or cure.
- Lupus symptoms can be severe, and highly unpredictable and can damage any organ or tissue, from the skin or joints to the heart or kidneys.
- Living with lupus can be baffling and isolating, as symptoms mimic other illnesses and often do not cause people to look sick.
- Common symptoms include extreme fatigue, headaches, painful or swollen joints, fever, anemia, butterfly-shaped rash on the face, photosensitivity, hair loss, abnormal blood clotting, mouth or nose ulcers, pain in chest on deep breathing and fingers turning white and/or blue when cold.
- While lupus can be disabling and potentially fatal, in many cases the most serious health effects can be managed through aggressive medical treatment and lifestyle changes.
- On average, it takes nearly six years for people with lupus to be diagnosed, from the time they first notice their lupus symptoms.
- People with lupus take on average nearly eight prescription medications to manage all of their medical conditions.

Lupus in America

- An estimated 1.5 million Americans have lupus.
- Lupus can strike anyone at any time, but 90 percent of the people living with lupus are women.
- Lupus usually develops between ages 15 and 44, and lasts a lifetime.
- Lupus is two to three times more prevalent among women of color -- African Americans, Hispanics/Latinos, Asians, Native Americans, Alaska Natives, Native Hawaiians and other Pacific Islanders -- than among Caucasian women.
- Despite the widespread prevalence of lupus, research on the disease has remained underfunded, relative to its scope and devastation.
- Only two drugs have ever been developed specifically to treat lupus and approved by the U.S. Food and Drug Administration.
- Awareness about lupus among Americans of all ages is extremely low, with 61 percent of Americans reporting they have never heard of lupus or know little or nothing about the disease beyond the name.
- The mean annual direct health care and lost productivity costs for people with lupus is \$20,000.

ABOUT THE LUPUS FOUNDATION OF AMERICA:

The Lupus Foundation of America is the only national force devoted to solving the mystery of lupus, one of the world's cruelest, most unpredictable and devastating diseases, while giving caring support to those who suffer from its brutal impact. Through a comprehensive program of research, education, support and advocacy, we lead the fight to improve the quality of life for all people affected by lupus.

Visit lupus.org to learn more and how to join the fight to end lupus.

2021 LEGISLATIVE PRIORITIES

LUPUS AT A GLANCE



An estimated 1.5 million Americans are living with lupus



Lupus annually costs the U.S. \$31.4 billion in direct and indirect expenditures



90% of people with lupus are women, but it can impact men and children



Women of color are 2-3 times more likely to develop lupus



On average, it takes 6 years to be diagnosed with lupus

Lupus is an unpredictable and misunderstood autoimmune disease that can ravage any organ in the body, from the skin or joints to the heart or kidneys. It is difficult to diagnose, hard to live with, and a challenge to treat: to date, there has been only one treatment approved specifically for lupus. Common lupus symptoms include extreme fatigue, joint pain, fever, anemia, hair loss, and abnormal blood clotting. There is no known cause of lupus and no cure. **Lupus is debilitating, destructive, and can be fatal.**

➤ **\$10.5 million for the National Lupus Patient Registry at the Centers for Disease Control and Prevention**

Researching the natural history, burden of disease, and treatment of lupus in the U.S.

Fiscal year 2021 funding: \$9.5 million

Continued and increased funding for the National Lupus Patient Registry will:

- Raise awareness and accelerate time to diagnosis, leading to improved care and outcomes for people with lupus and a reduction in health disparities;
- Identify how lupus affects those living with it and ways to improve its treatments;
- Examine the impact of lupus on children and teenagers;
- Continue the development of lupus disease management programs for patients.

➤ **\$15 million for the Lupus Research Program at the Dept. of Defense**

Funding high-impact research into the cause and treatment of lupus

Fiscal year 2021 funding: \$10 million

Continued and increased funding for the Lupus Research Program will:

- Determine why military personnel are at high risk of developing lupus;
- Further study the links between factors common to military service also known to be lupus triggers, like vaccines, chemicals, toxins, and ultraviolet light;
- Fund a higher percentage of the high-quality proposals the Dept. of Defense receives each year – in the program's first three years, only 38 of 334 proposals received funding, or less than 12 percent.

➤ **\$2 million for the lupus program at the Office of Minority Health**

Promoting lupus awareness and minority participation in lupus clinical trials

Fiscal year 2021 funding: \$2 million

Continued and increased funding for the Office of Minority Health will:

- Identify barriers inhibiting minorities from enrolling in lupus clinical trials;
- Continue the Office's work to develop and implement action plans to reach minority communities about clinical trials and facilitate their enrollment;
- Educate physicians about lupus and decrease the time to diagnosis.

➤ **\$46.1 billion for the National Institutes of Health**

Providing more funds for lupus research than any other public source

Fiscal year 2021 funding: \$42.9 billion

Continued and increased funding for the National Institutes of Health will:

- Support and bolster basic, clinical, and translational research across the country;
- Improve our understanding of the causes of lupus;
- Accelerate the discovery of genes associated with lupus and aid in the development of safe, effective treatments for the disease.

The Importance of Funding Lupus Research and Education

Congressional support is critical to the next breakthrough.

Help Us Solve
The Cruel Mystery
LUPUS[™]
FOUNDATION OF AMERICA

\$10.5 million for the National Lupus Patient Registry at the Centers for Disease Control and Prevention

Advancing our understanding of who gets lupus and how it affects those living with the disease

It is because of Registry-funded research that we have confirmed that women of color are 2 to 3 times more likely to develop lupus and are beginning to better understand the burden of the disease over the long term.

Reducing the time to diagnosis and raising awareness of the disease among medical professionals and the public

On average, it takes 6 years for a person to receive an accurate lupus diagnosis. Delayed diagnosis leads to increased hospitalizations and costs, both to the patient and the system, and the longer a person is not receiving proper care for lupus, the more likely irreversible damage to the body becomes.

Conducting first-of-its-kind research into the impacts of lupus on children and teenagers

CDC-funded research is learning more about childhood lupus, including a study following more than 1,000 pediatric lupus patients for at least 10 years. The federal government has never before funded this type of research, and is able to do so because of increased congressional support for the program.

Improving the quality of life for people living with lupus

The Registry supports the development of lupus disease management programs that help people with lupus better track and manage their symptoms, leading to improved outcomes and quality of life.

Increased funding for the National Lupus Patient Registry is critical to advancing our understanding of the disease, accelerating the diagnostic process, and improving the quality of life for people with lupus.

\$15 million for the Lupus Research Program at the Department of Defense

Advancing our understanding of why our military personnel may be at increased risk of developing lupus

Research has shown that post-traumatic stress disorder doubles the risk of autoimmune disease, including lupus. Other factors common to military service – including vaccines, chemical and toxin exposures, UV light, and infectious agents – have also been associated with the development of lupus. As the prototypical autoimmune disease, lupus is a key to understanding the link between autoimmunity and the military.

Funding high-risk, high-reward research not being conducted by other government agencies

Through their intensive review process and participation in the National Institutes of Health's Lupus Federal Working Group, the Department of Defense ensures that the research they fund does not duplicate the efforts of other government agencies, but rather builds on their efforts to maximize every dollar.

Becoming more relevant and important each year as the military continues to become more diverse

In 2018, women represented 16.5% of all active duty members, an increase of more than 7% since 2015. Of those more than 215,000 active duty women, greater than 56% are of color. As the military becomes more diverse in gender and ethnicity, the number of their personnel affected by lupus will increase.

Leaving the vast majority of high-quality proposals they receive unfunded

In its first 3 years, the Lupus Research Program has only been able to fund 38 of the 334 proposals submitted, or less than 12%. More congressional support will leave fewer potential breakthroughs on the shelf.

Congress recognized the connection between lupus and the military by establishing the Lupus Research Program in 2017, and continued support means more high-quality research into every aspect of lupus.

\$2 million for the lupus program at the Office of Minority Health

Addressing health disparities through clinical research

There is evidence to suggest that the lack of minority participation in lupus clinical trials exacerbates existing health disparities by creating confusion among providers about which lupus treatments are appropriate for minority patients. Representative trials would create better data and more clarity around a treatment's effects for all people with lupus.

Identifying barriers to minority enrollment in lupus clinical trials

Despite being disproportionately affected by lupus, minority populations have been historically under-represented in lupus clinical trials. A recent study found that in randomized controlled trials for lupus between 1997 and 2017, African Americans made up only 14% of enrollees despite making up a significantly larger percentage of people with lupus.

Educating and empowering physicians to promote clinical trials to people with lupus

While only 1% of the U.S. population participates in clinical trials, a 2013 study found that 72% believed they would participate in a trial if their doctor recommended it. The lupus program at the Office of Minority Health teaches primary care providers about lupus clinical research and how to speak to their patients about the benefits of participating.

Developing innovative ways to reach minority communities with information about lupus clinical trials

Beyond their doctor, there are many people and institutions that play a role in the health of a person with lupus. The Office of Minority Health's lupus program is working through faith-based institutions and community health workers to develop culturally competent materials, and a trusted voice to deliver them, to facilitate enrollment in lupus trials.

Increased funding for the lupus program at the Office of Minority Health will promote minority enrollment in lupus clinical research from all angles and address existing health disparities in lupus.

\$46.1 billion for the National Institutes of Health

Funding more lupus research than any public source in the world

In the last five years for which we have data, the National Institutes of Health have committed \$540 million to lupus research. Their research has advanced our understanding of the causes of lupus and provided valuable insights for researchers both inside and outside of the federal government to build on.

Conducting research into every aspect of lupus

Congressional support for the National Institutes of Health supports their vast portfolio of basic, clinical, and translational research across the country. This research is identifying new potential targets and genes associated with lupus to aid in the development of safe and effective treatments for the disease.

Involving the entire agency to better understand lupus and its effects

At least 16 different Institutes within the National Institutes of Health have funded lupus research recently, demonstrating the devastating and expansive scope of the disease.

Evaluating mesenchymal stem cells as a potential treatment for lupus

The National Institute of Allergy and Infectious Diseases has made a five-year commitment to co-fund a major phase II study into the use of mesenchymal stem cells to treat lupus. The study is currently ongoing and enrolling patients.

Robust funding for the National Institutes of Health is critical to advancing our understanding of the causes of lupus and supports the entire pipeline of lupus research, including drug development.

General lupus talking points

Lupus is a leading cause of death in women

A recent study found that lupus is the 10th leading cause of death for women ages 15–24.

Living with lupus is very expensive

According to a recent study, mean total costs for people with lupus can be as high as \$50,000 annually.

Nationally, lupus awareness is extremely low and likely contributes to delays in diagnosis

63% of Americans surveyed have never heard of lupus or know little or nothing about the disease and its symptoms.



JOIN THE CONGRESSIONAL LUPUS CAUCUS

Purpose

The Congressional Lupus Caucus provides a forum in which members of Congress and their staff can actively engage in a dialogue to improve the quality of life for people with lupus and their caregivers through supporting the advancement of lupus research and increasing awareness of lupus among the public and health professionals.

Caucus Co-Chairs

Bill Keating (D-MA)

Eddie Bernice Johnson (D-TX)

About Lupus

Lupus is an unpredictable and misunderstood autoimmune disease that ravages different parts of the body. It is difficult to diagnose, hard to live with, and a challenge to treat.

Lupus is a cruel mystery because it is hidden from view and undefined, has a range of symptoms, hits out of nowhere, and has no known cause and no known cure. Its health effects can range from a skin rash to a heart attack. Lupus is debilitating and destructive and can be fatal, yet research on lupus has not kept pace with research for other diseases of similar scope and devastation.

An estimated 1.5 million Americans and at least five million people worldwide have some form of lupus. Ninety percent of the people with lupus are women; however, men and children develop the disease as well. African American, Hispanic/Latinas, Asians, and Native Americans are two to three times more likely to develop lupus - a significant health disparity that remains unexplained. Furthermore, an accurate diagnosis of lupus can take as long as six years. For more information, visit www.lupus.org.

Join the Congressional Lupus Caucus Today

Members interested in joining the Congressional Lupus Caucus may do so by contacting [Tonia Wu](#) with Representative Eddie Bernice Johnson's office at 202-225-8885 or [Natalie Valentine](#) with Representative Bill Keating's office at 202-225-3111.



Lupus More Deadly for Asian and Hispanic Americans: Study

Steven Reinberg, HealthDay Reporter
Tuesday, Feb. 23, 2021 (via [HealthDay News](#))

More Asian and Hispanic people with lupus die prematurely than white patients, a new study reveals.

Death rates in San Francisco were nearly six times higher than expected among Hispanic patients with lupus and four times higher than expected among Asian women with lupus, the researchers found.

The higher death rate among racial and ethnic minority groups might result from more severe cases of the autoimmune disease or less access to care, said researcher Dr. Jinoos Yazdany. She is chief of rheumatology at Zuckerberg San Francisco General Hospital.

"It is very important that clinicians maintain a high index of suspicion for lupus in these groups in the primary care setting and refer patients to rheumatologists," Yazdany said. "Access to high-quality specialty care is important to improve the outcomes of this disease."

The study looked at more than 800 people with lupus in San Francisco from 2007 to 2009, as well as national death listings through 2017.

Just over 200,000 Americans have systemic lupus erythematosus, and minority women are at the highest risk, the study authors noted.

In lupus, the immune system mistakenly attacks healthy tissues, especially joints and skin. The condition can be fatal, and often causes debilitating fatigue and pain that prevent nearly half of adult lupus patients from working.

Of every 100,000 people in the United States, nearly 73 had lupus, for a total of 204,295 out of a population of 330 million, recent research shows. Nine times more women than men had the disease, and rates were highest among Native American/Alaskan Native women (at 270 per 100,000). Black women had the second highest rate (231 per 100,000), followed by Hispanic women (at 121 per 100,000).

Similar racial disparities were seen among men with lupus, with American Indians/Alaskan Natives having the highest number (54 per 100,000), followed by Black men (at 27 per 100,000), according to a recent report.

While the higher death rates in African Americans with lupus had been previously described, Yazdany said her team's study is one of the first studies to compare rates among Asian and Hispanic/Latino patients with the general population.

Dr. Karen Costenbader, chair of the Medical-Scientific Advisory Council at the Lupus Foundation of America, said that the new study is significant because it shows the high death rates among people with systemic lupus.

Continued...

The study showed that Black patients died about 7 years earlier than white patients, and Hispanics died nearly 10 years earlier.

"These figures are alarming and discouraging, as well," Costenbader said.

She said several factors probably underlie the disparities.

"[They] are due, to some extent, to genetic factors underlying disease severity and organ involvement, but also, and in large part, to social, cultural, educational, health care system, environmental, political and historical causes," Costenbader said. "Unfortunately, this includes ongoing systemic and institutionalized racism and barriers to access to the best medical care."

The first step to eliminating these disparities is awareness, she noted.

"But we need to do much more," Costenbader added. "We need more dedicated programs working to improve outcomes in lupus and to reduce these unacceptable disparities. We need work on many different fronts at once."

Dr. Waseem Mir, a rheumatologist at Lenox Hill Hospital in New York City, suspects that many minority patients with lupus aren't proactive about their care.

"The lack of health care education, what I've seen in my patients, is that a lot of these patients don't do follow-ups," Mir said. "They don't really take their medications, they don't really see the doctors as much and the way they should, so what happens is it leads to poor outcomes, and their health is also poor because they're not really eating well, they're not really exercising."

Solving these problems starts with the health care system and with doctors taking the time to educate their patients about the disease, he said.

Mir added that patients should be encouraged to learn about lupus and join support groups. But he also noted that many Asian and Hispanic patients have language barriers that prevent them from understanding how to take care of themselves.

Follow-up visits are particularly important, he said.

"Treatment follow-up is important just to assess the overall health of the patient and check if their disease is getting worse," Mir said.

The report was published Feb. 19 in the U.S. Centers for Disease Control and Prevention's *Morbidity and Mortality Weekly Report*.

[Read this article via U.S. News & World Report.](#)

SOURCES: Jinoos Yazdany, MD, MPH, chief, rheumatology, Zuckerberg San Francisco (Calif.) General Hospital; Karen Costenbader, MD, MPH, professor, rheumatology, Harvard University Medical School, Boston, and chair, Medical-Scientific Advisory Council, Lupus Foundation of America; Waseem Mir, MD, rheumatologist, Lenox Hill Hospital, New York City; *Morbidity and Mortality Weekly Report*, Feb. 19, 2021