

# The Importance of Funding Lupus Research and Education

*Congressional support is critical to the next breakthrough.*

Help Us Solve  
The Cruel Mystery  
**LUPUS**<sup>™</sup>  
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.

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**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.**

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## **\$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.

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**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.**

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## \$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.

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**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.**

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## \$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.

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**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.**

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## General lupus talking points

### Lupus is a leading cause of death in women

A recent study found that lupus is the 10<sup>th</sup> 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.