Help Us Solve
The Cruel Mystery

LUPUS
FOUNDATION OF AMERICA

FACTS ABOUT LUPUS:

Lupus is one of the cruelest, most mysterious diseases — an unpredictable and misunderstood autoimmune disease that ravages different parts of the body, causing the immune system to attack healthy tissue instead of fighting infections. It is difficult to diagnose, hard to live with, a challenge to treat and can be fatal.

COMMON SYMPTOMS OF LUPUS:

- Extreme fatigue
- Cognitive issues
- Painful or swollen joints
- Fever
- Anemia
- Butterfly-shaped rash on the face or other disfiguring rashes
- Photosensitivity
- Hair loss
- Abnormal blood clotting
- Mouth or nose ulcers
- Chest pain when breathing deeply
- Fingers turning white and/or blue when cold

What you need to know about lupus?

- Lupus symptoms can be severe, highly unpredictable, cause debilitating pain to many parts of the body, and can damage any organ or tissue, from the skin or joints to the kidneys, heart or lungs.
- There is no single test to diagnose lupus. On average, it takes nearly six years for people with lupus to be diagnosed, from the time they first notice their lupus symptoms.
- Lupus strikes without warning, affects each person differently, and has no known causes or cure.
- While lupus can be disabling and potentially fatal, in many cases its health effects can be managed through aggressive medical treatment and lifestyle changes.
- There are only three therapies developed specifically to treat lupus that are approved by the U.S. Food and Drug Administration.
- While lupus is a widespread disease, awareness of the disease lags behind many other illnesses. 63% of Americans surveyed have never heard of lupus or know little or nothing about this disease and its symptoms beyond the name.
- Despite the widespread prevalence of lupus, research on the disease has remained underfunded, relative to its scope and devastation.

Who has lupus?

- An estimated 1.5 million Americans have lupus.
- Ninety percent (90%) of the people living with lupus are women, however, men, children and teenagers develop lupus, too.
- Lupus can strike anyone at any time, but usually develops between ages 15 and 44, and lasts a lifetime.
- Lupus is two to three times more prevalent among African American, Hispanic/Latina, Asian American, Native American, Alaska Native, Native Hawaiian and other Pacific Islander women than among White women.

Lupus takes a significant toll, the burden on daily life can be devastating.

- **Lupus is ranked the fifth cause of death among Black and Hispanic women, ages 15-24,** and a leading cause of death among all young women.
- **55%** of people with lupus say they can no longer work full-time due to lupus complications.
- **76%** of lupus patients say fatigue caused by lupus has forced them to cut back on social activities.
- The average annual total costs for people with lupus (combining direct and indirect costs) can be as high as **$50,000**.
- People with lupus take on average nearly **eight prescription medications** to manage all their medical conditions caused by the disease.

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ABOUT THE LUPUS FOUNDATION OF AMERICA:

The Lupus Foundation of America is the largest national organization devoted to improving the quality of life for all people affected by lupus through programs of research, education, support and advocacy.

WE ARE FOCUSED ON THREE STRATEGIC OUTCOMES:

Reducing Time to Diagnosis

Ensuring People with Lupus Have an Arsenal of Safe and Effective Treatments

Expanding Direct Services and Increasing Access to Treatments and Care

Our vision is a life free of lupus and what we strive toward each and every day. We know we won't achieve it alone—that's why we need more people like you to get involved so together we can make the greatest impact in the fight against lupus.

VISIT LUPUS.ORG TO LEARN MORE ABOUT LUPUS AND HOW YOU CAN GET INVOLVED.

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PROVIDING SUPPORT, RESOURCES AND RAISING AWARENESS

Living with lupus can be challenging and life-changing, but it does not have to be faced alone. We at the Lupus Foundation of America are here to listen, to provide caring support and answers through hundreds of trustworthy resources and tailored support services that cover every aspect of lupus. Our health education specialists and national network of regional offices, chapters and volunteers guide individuals and families through the complexities of lupus and host a range of support groups and education programs. And we work tirelessly to raise global awareness and increase the understanding of lupus and its impact among local communities and health care providers, helping reduce the time to diagnosis. **Learn more at: Lupus.org**

ATTACKING LUPUS FROM EVERY DIRECTION

We are tackling lupus from every direction. Through our research efforts we have funded more than 400 studies and 250 fellowships working to identify the causes of lupus, discover better ways to control symptoms, find pathways to new treatments and ultimately a cure. We not only drive research to deliver the most significant impact on peoples' lives in the shortest time possible, we work to address the root problems that interfere with scientific progress and set a course to solve them. We are also committed to addressing the factors that contribute to healthcare and health outcome disparities in populations living with the highest burden of lupus. Find out more about our research program at **Lupus.org/Research**

ADVOCATING FOR PEOPLE WITH LUPUS

Every day we fight to ensure the government is responsive to the needs of people with lupus. We work with elected officials in the House and Senate to support policies to improve the lives of people with lupus and ensure equitable access to care. We also work with federal agencies like the Food and Drug Administration to overcome regulatory hurdles and incorporate patient perspectives into the drug development and approval process, and with state health programs to provide compassionate care to the people who need it most. Our advocacy team is backed by tens of thousands of lupus advocates across the nation. Working with our advocates and congressional allies, we've generated more than $684 million in federal research funding for lupus in the last five years alone. The patient voice is one of the most powerful tools toward helping us continue to drive change. Find out more about becoming an advocate at **Lupus.org/Advocate**

SEPTEMBER 2023