

# Investment in research saves lives and money



facts about:

## Lupus

Lupus is a chronic, inflammatory, autoimmune disease that occurs when an individual's immune system attacks its own tissues and organs. There is no known cure for lupus and only one FDA-approved drug developed specifically for lupus is available.\*\*+

*"If you think research is expensive, try disease."*

- Mary Lasker 1901-1994

### Today:

- It is estimated that lupus affects as many as 1.5 million Americans, and 90% are women. ♦
- It is estimated that between 10 and 15% of people with lupus will die prematurely due to lupus-related complications. ♦
- Women of color are up to three times more likely to develop lupus than white women. †
- There are many different types of lupus, varying in cause and impact sites. The three most common types of lupus are systemic lupus erythematosus (SLE), cutaneous and drug-induced. In the majority of cases the cause of lupus is unknown.\*
- One-fifth of those with lupus have a parent or sibling who has been, or will be, diagnosed with lupus. Additionally, 5% of children who have a parent with lupus will develop the condition. †

### The Cost:

- The total annual economic burden of lupus is estimated to be as much as \$52,415 per person. ‡
- For individuals receiving Medicare, those diagnosed with lupus have, on average, more than twice the physician visits, hospitalizations and emergency room visits per year than individuals without lupus. This increased care results in an additional \$10,229 per patient per year in direct health care costs for each Medicare beneficiary with lupus. □
- Two of three lupus patients report no longer being able to work full time due to lupus. ♦

♦ NATIONAL PUBLIC HEALTH AGENDA FOR LUPUS, 2015. + MAYO CLINIC <WWW.MAYOCLINIC.ORG>  
 □ GARRIS, C. ET AL. COST EFF RESOUR ALLOC, 2015. 13(9). Δ NATIONAL BURDEN OF LUPUS SURVEY, 2011.  
 ♦ LUPUS FOUNDATION OF AMERICA <WWW.LUPUS.ORG>  
 \* CENTERS FOR DISEASE CONTROL AND PREVENTION <WWW.CDC.GOV>  
 ^ LUPUS RESEARCH INSTITUTE <LUPUSRESEARCHINSTITUTE.ORG>  
 ‡ MEACOCK, R. ET AL. PHARMACOECONOMICS, 2013. 31(1):49-61.

### perspective:



NAME: Mallyory Dixon  
 AGE: 30  
 CONDITION: Lupus

From the time she was a teenager, Mallyory Dixon has been in and out of hospitals fighting lupus. Her symptoms began with joint pain, which led doctors to first diagnose her with rheumatoid arthritis at age 17. But over time Mallyory also developed problems with her heart, lungs, kidneys and nervous system. When she was 23 she was diagnosed with lupus.

Since then, she has spent more than 150 days in a hospital bed because of lupus-related problems – the longest stay lasting 86 days. During her time in the hospital, Mallyory has undergone several blood transfusions, dialysis, plasma exchanges, multiple ventilations, and a tracheotomy. At one point, she was considered clinically dead and had to be resuscitated. Mallyory was in a medically-induced coma for more than a month. Once she regained consciousness, she spent time on a ventilator and received dialysis and chemotherapy before she was finally released from the hospital. After narrowly surviving such a severe flare, Mallyory was determined to gain control of her disease. She quickly found a new team of doctors to develop a treatment plan.

Mallyory now believes that getting diagnosed is not the toughest challenge of having the disease – it is learning to develop a 'lupus plan' for her life. Fighting lupus over the past ten years has not been easy, but despite her struggles Mallyory has learned to be strong. Now she is committed to encouraging other people with lupus to find strategies that work in their own lives, in addition to spreading awareness about the signs and symptoms of lupus to promote early diagnosis. She also encourages people with lupus to become intimately familiar with their disease so they can pin-point the triggers that cause their flares and live a healthy, active lifestyle while respecting their limitations. Mallyory participated in the Lupus Foundation of America's KNOW Lupus campaign, which is just one of the many ways she works to raise awareness of lupus.

SAVING LIVES  
 SAVING MONEY

### HOW RESEARCH SAVES LIVES:

- In the 1950's, only 50% of individuals with lupus lived more than 5 years following their diagnosis. With improvements in medical interventions, a better clinical understanding of the disorder and careful monitoring, between 80 and 90% of individuals diagnosed with lupus can now expect to have a normal lifespan.\* ‡
- Belimumab, the only FDA-approved treatment developed specifically to treat lupus, was found to reduce an individual's lupus-associated symptoms by 50% in nearly half of the study participants receiving the medication. Patients who received belimumab also experienced a reduction in emergency department visits and hospitalizations compared to patients who did not receive the medication. †

### HOW RESEARCH SAVES MONEY:

- Improved clinical understanding of lupus has led to earlier diagnosis and intervention, which has not only improved health outcomes and reduced mortality, but has also reduced health care costs. Individuals with lupus who are diagnosed early are less likely to be hospitalized or suffer from 'flare-ups,' a resurgence of lupus-associated symptoms, than individuals who were diagnosed later in their disease progression. When individual are diagnosed earlier their monthly health care and hospitalization costs are on average nearly 18% and 30% lower respectively. ^

\* LUPUS RESEARCH INSTITUTE <LUPUSRESEARCHINSTITUTE.ORG>  
 † URAMOTO, K. ET AL. ARTHRITIS & RHEUMATISM, 1999. 42 (1): 46-50.  
 ‡ COLLINS, C. E. ET AL. LUPUS SCI MED, 2016. 3(1).  
 ^ OGLESBY, A. ET AL. APPLIED HEALTH ECONOMICS AND HEALTH POLICY, 2014. 12(2).

# facts about: } Lupus

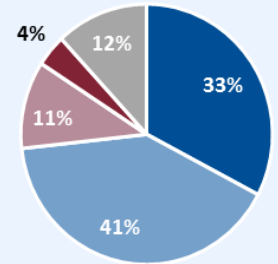
“My hope would be that we take this exceptional scientific moment and unleash all of the talent of those investigators out there who are ready to push back the frontiers and discover all kinds of things about what causes lupus and what can we do about it.”

- Dr. Francis Collins, Director  
National Institutes of Health

## National Poll: Majority say research has improved health

*Do you mainly agree or disagree that your health has been improved thanks to research over the course of your lifetime?*

A RESEARCH!AMERICA POLL OF U.S. ADULTS CONDUCTED IN PARTNERSHIP WITH ZOGBY ANALYTICS IN JANUARY 2016.



■ Strongly Agree  
■ Somewhat Agree  
■ Somewhat Disagree  
■ Strongly Disagree  
■ Not Sure

## Hope for the Future:

**BIOMARKERS IN CHILDREN:** Up to 80% of children and teens with lupus will develop kidney inflammation (lupus nephritis). If not adequately controlled, lupus nephritis can lead to kidney failure, the need for chronic kidney dialysis or transplantation, and even death. New research being conducted at the Children’s Hospital of Philadelphia may lead to the development of the first urine test to assess disease activity in the kidneys. Such a test has the possibility of replacing painful biopsies that currently serve as the gold standard for assessing damage in the kidneys. Biomarkers identified in this study may also have the potential to serve as treatment targets, allowing for more personalized care for children with this devastating manifestation of lupus.\* ^

**DATA SHARING TO IMPROVE LUPUS CLINICAL TRIALS:** Lupus is a complex disease, making the development of safe and effective treatments difficult. The Lupus Foundation of America Collective Data Analysis Initiative (LFA CDAI) is a unique collaboration among multiple biotechnology companies with the shared goal of improving our ability to deliver new treatments. LFA CDAI combines data from industry-sponsored lupus clinical studies from across the world to identify trends and gain new insights into clinical trial design. The results of LFA CDAI are enabling researchers who design lupus clinical trials to better determine whether an investigational treatment truly has advantages over current treatments options. This ongoing work by LFA CDAI will accelerate the development of new therapies for lupus.\*

**UNCOVERING THE CAUSES OF LUPUS:** Epigenetics is the study of factors that influence whether genes are turned on (active) or off (silenced) when cells are replicated. These modifications sometimes occur as a result of influences in the environment, such as diet and sunlight. Ongoing studies on the role of epigenetics in lupus are enabling researchers to identify genes affected by environmental factors and how they possibly contribute to lupus. In the future, these studies may allow us to find new treatment targets for lupus, as well as prevent the development and progression of lupus.\*

**TRANSFORMATIVE TREATMENTS:** Adult stem cell therapy may hold promise as a safe and effective alternative for people with lupus who do not benefit from the current treatments available. This treatment could potentially help lower dosage of more toxic treatments, diminish the long-term effects of lupus, stop damage to vital organs and save lives. Previous research using this type of therapy for lupus has reported positive results. Like every potential new therapy, FDA-approved clinical trials are needed to truly determine whether this treatment can make a difference in the lives of people with lupus.\*

\* LUPUS FOUNDATION OF AMERICA <WWW.LUPUS.ORG>  
^ CAMERON, J.S. PEDIATR NEPHROL, 1994. 8 (2): 230-249.

## The Bottom Line:

*Very little is known about the cause of lupus, and even less is known about the best ways to treat, and ultimately cure, this insidious disease. Without ramped up investment in research to increase our knowledge about who is impacted, the progression of the disease, and approaches to combat lupus’ deadly complications, Americans will continue to die every year from this poorly understood condition.*

## Research!America

241 18<sup>th</sup> Street South, Suite 501  
Arlington, VA 22202  
703.739.2577  
www.researchamerica.org  
info@researchamerica.org

For additional information on lupus:  
Lupus Foundation of America  
[www.lupus.org](http://www.lupus.org)  
Lupus and Allied Diseases Association  
[www.nolupus.org](http://www.nolupus.org)

*The Albert and Mary Lasker Foundation is a founding partner in this series of fact sheets. [www.laskerfoundation.org](http://www.laskerfoundation.org)*