

# What You Need to Know *About* **Lupus**

A COMPLEX AUTOIMMUNE DISEASE



LUPUS  
RESEARCH  
ALLIANCE



NATIONAL  
Minority Quality Forum



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# AGENDA

## 1 Welcome

## 2 Facts on Lupus

- What is it?
- Who gets it?
- How is it diagnosed and treated?

## 3 Getting Involved in Lupus Research

# WHAT IS LUPUS?

- Lupus is a chronic disease of the immune system
- Our immune system is our body's defense against infection and other diseases
- With lupus, our immune system starts to attack our own body in different ways
- This can lead to inflammation and tissue damage to any part of the body, particularly in the:
  - Joints              – Kidneys              – Skin              – Heart
  - Brain              – Blood Vessels              – Lungs
- The cause of lupus is unknown, but genetics, environment and hormones are believed to play a role
  - Lupus can run in families
- Lupus is heterogenous – it affects each person differently
- It is not contagious





# WHO GETS LUPUS?

*Estimated*  
**161,000 - 322,000**  
**PEOPLE IN THE U.S.**  
*are living with lupus*

*Anyone can get lupus, but some are at greater risk:*



**Women between  
ages 15-44**



**Black/African American,  
Hispanic/Latino, Asian, or  
Native American individuals**



**Family history of lupus  
or autoimmune disease**

Helmick CG, Felson DT, Lawrence RC, et al. Estimates of the prevalence of arthritis and other rheumatic conditions in the United States: Part I. Arthritis Rheum. 2008;58(1):15–25. PubMed PMID: 18163481. doi: 10.1002/art.23177. abstract

# TYPES OF LUPUS

## Systemic Lupus Erythematosus (SLE)

- Most common type of lupus
- Affects many parts of the body

## Cutaneous (Skin) Lupus

- Causes a rash or lesion on the skin
- Typically triggered by exposure to sunlight
- Discoid is the most common type of cutaneous lupus

## Drug-Induced Lupus

- Caused by a reaction to certain medications
- Symptoms usually disappear when medication is stopped

## Neonatal Lupus

- Rare condition where mother's SLE antibodies are shared with the fetus
- Usually resolves with no long term effects

# WHAT ARE THE MOST COMMON SIGNS & SYMPTOMS?

*No two cases of lupus are the same, depending on the organs affected, people may experience different symptoms*



## FATIGUE

50-90% of people with lupus identify fatigue as a main symptom



## MALAR RASH

Other common symptoms include skin rashes and hair loss



## JOINT PAIN & SWELLING

Up to 90% of people with lupus will have joint inflammation or swelling



## FEVER

Most people with lupus experience unexplained fevers



# LUPUS SYMPTOMS COME AND GO

## Lupus symptoms can:

- Be mild, moderate or severe
- Persist or go away
- Come on suddenly or over time

## A sudden onset of lupus disease activity is called a 'flare'

Flares may be characterized by any group of symptoms that can affect many different parts of the body

## Lupus flares may be triggered by:

- Stress
- Sunlight exposure
- Weather/temperature changes
- Infection
- Other factors

## Lupus can go into remission

Remission is a period of low disease activity and can last months or years





# HOW IS LUPUS DIAGNOSED?

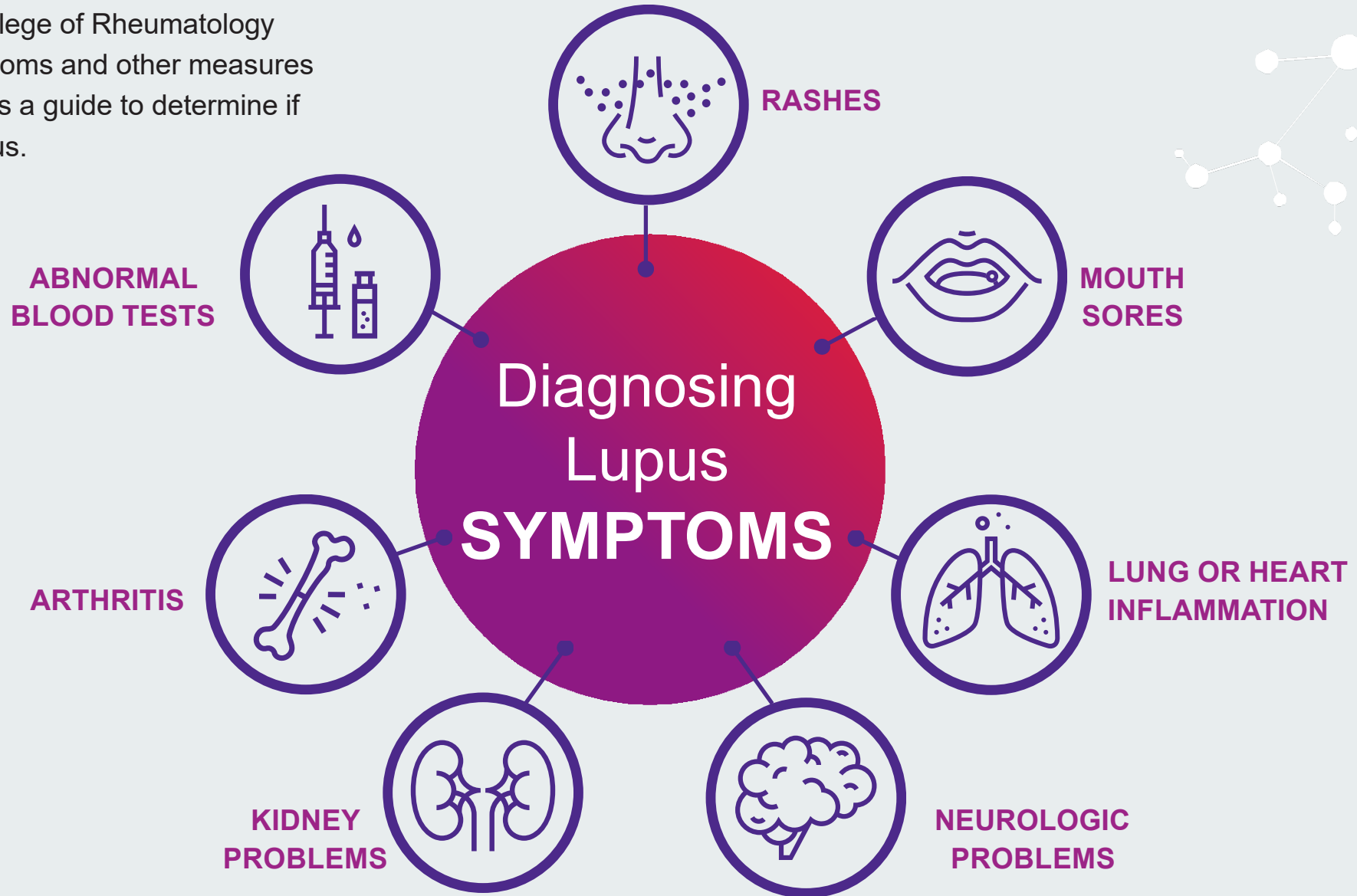
**Lupus is difficult to diagnose because it affects every person differently, can impact almost any organ, mimics other diseases, and can even change within the same person**

**Healthcare providers typically make the diagnosis based on:**

- Medical history
- Physical exam
- Blood tests
- Skin and/or kidney biopsies



The American College of Rheumatology has a list of symptoms and other measures that doctors use as a guide to determine if a person has lupus.



# TWO COMMON & SERIOUS COMPLICATIONS OF SLE

**1** Neuropsychiatric SLE (NPSLE)

**2** Lupus Nephritis (LN)

# 1

## NEUROPSYCHIATRIC SLE (NPSLE)

- Neuropsychiatric lupus describes feelings of depression, headaches, and lupus fog – trouble thinking or remembering due to lupus
- Neuropsychiatric lupus affects 80-90% of people with lupus.
- 25% of lupus patients experience major depression and 37% have major anxiety, research shows.
- Healthcare providers can help relieve mental health issues caused by lupus, often by changing medications or adding one for anxiety or depression.



# 2

## LUPUS NEPHRITIS (LN)

- Lupus nephritis – inflammation of the kidneys -- occurs in up to half of people with lupus.
- Renal/kidney inflammation can go undetected and can lead to renal failure and dialysis.
- Regular monitoring of urine and blood pressure is important.
- Signs include blood in the urine or foamy urine which can mean that there is excess protein; swelling of legs, ankles, hands or tissue around the eyes; weight gain due to fluid the body isn't getting rid of; high blood pressure; joint/muscle pain; high levels of waste (creatinine) in the blood; and impaired/failing kidney.
- Invasive surgical biopsies may be used to diagnose lupus nephritis.
- Serious outcomes can be prevented by seeking treatment at the first signs of kidney disease.
- There are now two approved treatments for lupus nephritis – Benlysta® (belimumab) and Lupkynis™ (voclosporin).

# HOW IS LUPUS CURRENTLY TREATED?

**Treatment depends on symptoms. While there is no cure, treatments can help you feel better and improve symptoms. The goals of treatment are to:**

- Prevent flares
- Treat symptoms when they happen
- Reduce organ damage and other problems

**Treatment might include medicines that:**

- Reduce swelling and pain
- Calm the immune system to prevent it from attacking the organs and tissues in your body
- Reduce or prevent damage to organs and joints

**Medicines commonly used to treat lupus symptoms include:**

- Nonsteroidal anti-inflammatory drugs (NSAIDs)
- Corticosteroids
- Antimalarial drugs
- BLYS-specific inhibitors
- Immunosuppressive agents/chemotherapy

**Only three medicines have been specifically developed for lupus:**

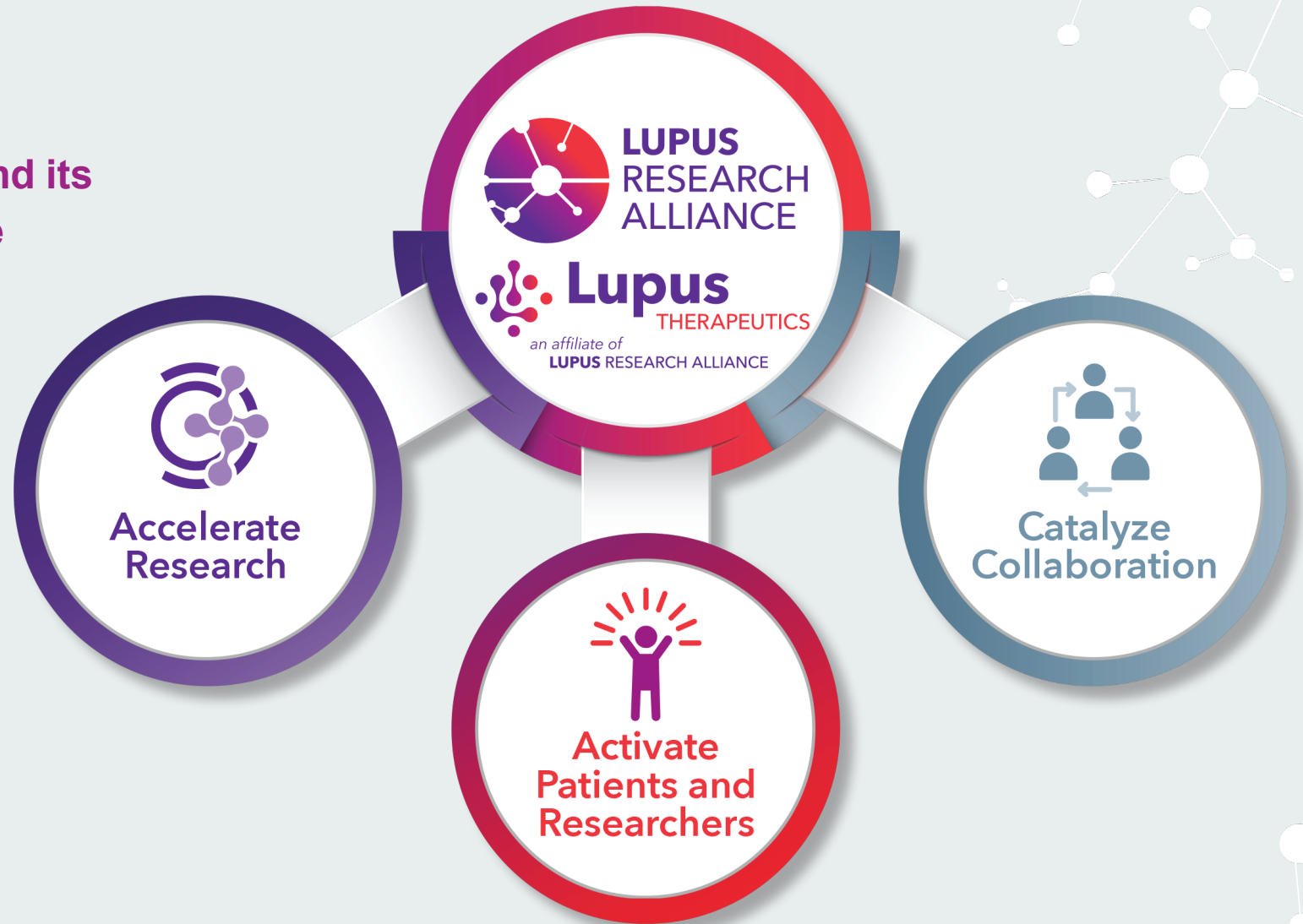
- Benlysta® (belimumab) – for general lupus and lupus nephritis
- Lupkynis™ (voclosporin) – for lupus nephritis
- Saphnelo™ (anifrolumab-fnia) - for general lupus

# FINDING A CURE

**The Lupus Research Alliance and its affiliate Lupus Therapeutics are transforming lupus care**

by advancing research and supporting each research stage from basic science in the lab through clinical research and trials

**The end goal: to accelerate the development of new treatments and a cure for people with lupus**



# LEARN ABOUT CLINICAL TRIALS

**Better treatments are only possible with results of clinical studies.** Sometimes people refer to clinical trials as clinical research.

**Clinical research** is the study of health and illness in people intended to add to our medical knowledge. Studies involve human volunteers (or participants).

**There are two main types of clinical studies:**

- Interventional
- Observational





# TYPES OF CLINICAL STUDIES

## Interventional Studies

(also known as clinical trials) are studies where researchers test new ways to prevent, detect, or treat disease.

- Participants are assigned to groups that receive one or more intervention/treatment (or no intervention) so researchers can evaluate the effects of the interventions on health outcomes.
- Which treatment each participant receives is determined by the study's protocol that outlines its objectives, design, and methods.

## Observational Studies

allow scientists to find an association between things but cannot prove that one thing causes another.

- Data are collected by monitoring volunteers and may include answering surveys and providing biological samples such as blood or urine.
- Can help researchers come up with a hypothesis to later test in a clinical trial.

# CONSIDER TAKING PART IN A CLINICAL TRIAL

## What is the purpose of a clinical trial?

**Clinical trials help to answer the question, “will this drug help people and is it safe?”**

- Clinical trial volunteers work with researchers to find safer, more effective ways to diagnose, prevent, and ultimately cure lupus

### Advantages

- Take greater control over your health and care
- Close attention to your treatment by experts in the field
- Try cutting-edge potential treatments before they are available
- Help others with lupus by advancing research

### Disadvantages

- Treatment may not work
- Side effects are possible
- Can take more time and effort with clinic visits and at-home monitoring

“



*Emotionally, taking part in a trial is very empowering. I feel like I have a sense of responsibility to the lupus community to do everything I can to help everyone dealing with this disease.*

– Kaamilah

# THE IMPORTANCE OF INCREASING DIVERSITY IN CLINICAL RESEARCH

- Participants in clinical trials must reflect the demographics of the disease the product is intended to treat to know that it is safe and effective for those people
- A recent review of lupus trials found 51% of trial participants were white, 21% Hispanic and 14% were Black while Black people make up 43% of lupus cases
- This is not unique to lupus. Participation in clinical trials by people who are Black has decreased in recent years
- Low participation by minority populations in lupus clinical trials results in a lack of clinically significant data on the effectiveness, safety, and side effects of treatment within populations at greatest need
- Barriers to participation include mistrust of the research and community, lack of access to healthcare, lack of understanding and knowledge about clinical research, and challenges healthcare providers have in referring patients to trials. Also, healthcare providers may not ask minorities to participate.
- COVID-19 highlighted many of these issues. Lupus Therapeutics is working with its Lupus Clinical Investigators Network, the pharmaceutical industry, clinical researchers, healthcare providers, and people with lupus to make clinical trials more diverse and patient-centric

# WHAT IS THE LRA/LT DOING TO ADVANCE RESEARCH AND ENSURE DIVERSITY?

## Ensuring people of color have the opportunity to join clinical trials by:

- Supporting patients with lupus at major medical centers on their decision to get involved in clinical trials through our Patient Advocates for Lupus Studies (PALS) program
- Organizing the MultiCultural Outreach Task Force to educate people of color about lupus and research
- Educating people of all races and ethnic backgrounds about ways to get involved in clinical research including collaborations with groups like the National Minority Quality Forum

## Encouraging people of color to pursue science/research careers

- Fostering diversity among lupus researchers by awarding grants to pursue careers in the field
- Mentoring new researchers to promote career success and retention



# WHAT TO DO IF YOU SUSPECT LUPUS



## WRITE DOWN YOUR SYMPTOMS

and talk to your healthcare provider



## ASK YOUR DOCTOR

to refer you to a rheumatologist



## VISIT THE LUPUS RESEARCH ALLIANCE WEBSITE

and learn more: [lupusresearch.org](https://lupusresearch.org)

# HOW CAN YOU GET INVOLVED?

If you have lupus, talk to your doctor  
about clinical trial opportunities

Raise awareness of lupus by talking  
to your family and friends

Learn more about lupus and the Lupus  
Research Alliance at [LupusResearch.org](https://LupusResearch.org)

Explore the many ways you can contribute  
to advance lupus research

**YOU CAN BE PART OF THE SOLUTION FOR  
BETTER TREATMENTS AND A CURE!**



# LEARN MORE

Lupus Research Alliance: [lupusresearch.org](https://lupusresearch.org)

Lupus Clinical Trials: [lupusresearch.org/trials](https://lupusresearch.org/trials)



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## Lupus is a chronic disease of the immune system.

Lupus is a chronic and complex autoimmune disease that may cause widespread inflammation and tissue damage, especially in the brain, lungs, heart, and kidneys.

The cause of lupus is unknown, but genetics, environment and hormones are believed to play a role. Lupus is not contagious.

## Lupus can be misdiagnosed.

Other conditions that may look like lupus include infections, cancers, or inflammatory diseases.

There is no single test to diagnose lupus. Diagnosis is confirmed by a combination of physical exams, lab tests, and medical history.

## Symptoms of lupus vary.

Symptoms vary, but the most common symptoms of lupus include:



## Symptoms may:

- Be mild, moderate or severe
- Persist or resolve
- Come on suddenly or over time

## Anyone can get lupus

However, some are at greater risk:

- Women between ages 15-44
- Black/African American, Hispanic/Latino, Asian, or Native American individuals
- Family history of lupus or autoimmune disease

## Two most common complications of lupus:

- 1 Neuropsychiatric SLE (NPSLE)**  
Describes feelings of depression, headaches, and lupus fog
- 2 Lupus Nephritis (LN)**  
When the kidneys become affected by lupus, it is called lupus nephritis

## Who treats Lupus?

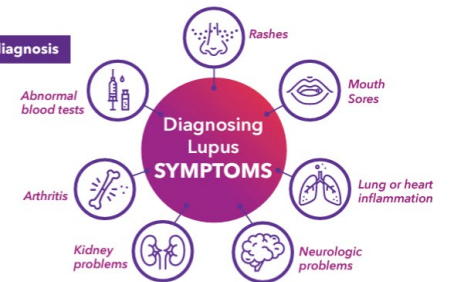
Lupus is generally treated by a team of physicians led by a rheumatologist. A rheumatologist specializes in arthritis and other inflammatory diseases.



## Criteria for lupus diagnosis

No two cases of lupus are the same, which makes lupus difficult to diagnose.

However, the American College of Rheumatology has a list of symptoms and other measures that doctors use as a guide to determine if a person has lupus.



## If you think you have lupus...

- Write down your symptoms and talk to your health care provider
- Ask your doctor to refer you to a rheumatologist
- To learn more, go to the Lupus Research Alliance website: [lupusresearch.org](https://lupusresearch.org)

This fact sheet is part of an education program. If you are interested in learning more about how you can spread lupus awareness, contact [advocacy@lupusresearch.org](mailto:advocacy@lupusresearch.org) and ask about the What you need to know about Lupus Toolkit.



# ACKNOWLEDGMENTS

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**GOLD**



**SILVER**



**BRONZE**



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