

**Lupus Awareness Month
Campaign Media Kit**

There's More to **LUPUS** Than You Know



2000 L Street, N.W., Suite 710
Washington, DC 20036
202-349-1155
info@lupus.org ♦ www.lupus.org



There's More to **LUPUS** Than You Know

Dear Media Representative,

Every day, 1.5 million Americans (enough people to fill thirty baseball stadiums) struggle with the disabling and life-altering impact of lupus, a chronic autoimmune disease. Lupus occurs when the immune system is unbalanced, causing it to become destructive to any major organ or tissue in the body. Lupus can be very unpredictable and is potentially fatal, yet no satisfactory treatment or cure exists.

Why is awareness of lupus important? **To save lives!** Consider these facts:

- Lupus can attack the body for years before the disease is diagnosed. Symptoms of lupus mimic common illnesses and often are dismissed as nothing serious.
- More than half of the people with lupus suffer four or more years and visit three or more doctors before receiving a correct diagnosis.
- Awareness of lupus is lowest among women 18-24 – the age group most likely to develop the disease.
- Late diagnosis and delayed treatment contribute to poor outcomes and increased morbidity and mortality.
- Lupus is a serious disease that can damage vital organs, such as the kidneys, heart, lungs, and brain. The disease can cause seizures, strokes, heart attacks, miscarriages, and organ failure leading to significant disability or death.

But there is hope.

Early diagnosis and proper medical care greatly improve the quality of life for people with lupus. The Lupus Foundation of America (LFA) seeks to educate the public about early warning signs of lupus and all aspects of living and coping with the disease.

With your help, we can prevent needless suffering through increased awareness of lupus. The enclosed materials are provided to support this effort. Additional resources are available from the Lupus Foundation of America Website at www.lupus.org or from your local LFA chapter. A list of chapters appears on the LFA Website.



There's More to **LUPUS** Than You Know

Public Lacks Awareness of Serious Disease with Life-Threatening Complications

May is National Lupus Awareness Month

(Washington, DC – LFA) While most Americans are aware of the signs and health risks of breast cancer or heart disease, relatively few are aware of another significant health problem that disproportionately strikes young women between the ages of 15 and 45. The disease is lupus. Lupus is caused by an unbalanced immune system that can be destructive to any major organ or tissue in the body. Lupus can be very unpredictable and is potentially fatal. (Attachment #1)

While more than 1.5 million Americans have lupus, many individuals still are unaware of the potentially disabling and life-threatening health effects of lupus. The disease is two to three times more common among African Americans, Hispanics/Latinos, Asians, and Native Americans than among Caucasians – but no one is safe from lupus.

What is most troubling about the lack of awareness of lupus is that early recognition, diagnosis and proper medical care of lupus often can prevent or reduce serious health complications, such as heart disease, strokes, seizures, and kidney failure. (Attachment #2)

May is National Lupus Awareness Month. Now in its thirty-first year, Lupus Awareness Month is observed to disseminate medically sound information about lupus, increase public understanding of the physical, emotional, and economic impact of the disease, and provide support, services, and hope to all people affected by lupus.

Lupus Can Damage Any Organ System

Lupus is more than joint pain, fatigue, fevers, and skin rashes – common symptoms of the disease. Inflammation caused by lupus can damage the heart, lungs, kidneys, and brain, resulting in significant disability or death.

- Women with lupus have a five- to ten-fold increased risk of coronary heart disease.
- Approximately 40 percent of people with lupus will develop nephritis, or kidney disease.
- People with lupus are at high risk for blood clots, stroke, and seizures.
- Without intervention and treatment, the outlook for people with lupus can be poor.

Diagnosis of Lupus Can Be Difficult

Lupus is difficult to detect and diagnose because many initial symptoms of the disease often are dismissed as nothing serious. (Attachment #3) Because the disease develops most often in young adults, and disease activity comes and goes over time, it is not uncommon for people with lupus to suffer several years before doctors can make an accurate diagnosis. On average, people with lupus experience symptoms for four or more years and visit three or more doctors before they are able to obtain a correct diagnosis. Currently, there is no single laboratory test that can determine whether a person has lupus. Diagnosis is usually made by a careful review of a person's entire medical history, coupled with an analysis of the results obtained from routine laboratory tests and some specialized tests related to immune status. The Lupus Foundation of America Website includes a short questionnaire that can help

(Continued on the next page)



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Public Lacks Awareness of Lupus (Page 2 of 2)

individuals determine whether they need to consult with a doctor about lupus. (Attachment #4) Visit the LFA Website at www.lupus.org or call toll-free 1-888-38-LUPUS (1-888-385-8787) to obtain a copy.

Treatments Can Cause Other Health Problems

Once a diagnosis is made, however, people with lupus face other challenges. There is no cure for the disease, and current treatments (Attachment #5) may cause other health problems that can be worse than the primary disease. There has been no new drug approved by the U.S. Food and Drug Administration (FDA) specifically for lupus in nearly 50 years.

Research Offers Promise for New Treatments

Despite the current lack of new treatments for lupus, the future is brighter today than ever before. There is great hope that new, safe and effective therapies will be available in the near future. A robust pipeline exists of potential new drugs in various stages of clinical development. In addition, new information about how the immune system functions is providing insight into the progression of lupus and ways to impede or halt disease activity. Through its own research program, the Lupus Foundation of America is advancing research on the disease by bringing down barriers that have obstructed the drug development process. The LFA research program's primary objectives are to search for the causes of and cure for lupus and speed clinical studies of potential new therapies.

LFA Leads National Effort to Educate Health Professionals and the Public

As part of its comprehensive mission, the LFA translates research findings into medically sound information and programs for individuals with lupus, their families, and health professionals. The LFA has a new education series of booklets and fact sheets on all aspects of lupus, and publishes a national magazine, **Lupus Now®**, which includes the latest information on new treatments and therapies, clinical updates, lifestyle and wellness feature articles, personal stories, and more.

The LFA Website is the best source for lupus information, according to a study presented at the American College of Rheumatology Annual Scientific Meeting. The Foundation's Website offers lupus information for all audiences, Webchats with renowned lupus experts, message boards, Ask the Experts, and newsletters which provide reports on developments in lupus research and advocacy, as well as tips for living and coping with the disease.

The LFA has a national network of patient navigators who answer questions, provide referrals, and help people with lupus access services they need to improve their health and quality of life. The LFA also has a nationwide network of nearly 300 chapters and support groups in 32 states operating programs of research, education, and advocacy. LFA programs assist people with lupus, their families, and health professionals by providing knowledge, support, and hope.

For more information about lupus and the LFA, please visit the LFA Website at www.lupus.org.

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There's More to **LUPUS** Than You Know

Important Facts about Lupus

(Attachment #1)

Definition of Lupus

- Lupus is an acute and chronic (lifelong) autoimmune disease in which the immune system is unbalanced, causing inflammation and tissue damage to virtually every organ system in the body.
- Lupus can affect many parts of the body, including the skin, joints, blood and blood vessels, heart, lungs, kidneys, and brain.
- The health effects of lupus range from mild to life-threatening and the disease vacillates between periods of increased activity, called flares, and periods of remission.
- Lupus can be particularly difficult to diagnose because its symptoms are similar to those of many other illnesses, and major gaps exist in understanding the causes and consequences of lupus. More than half of all people with lupus suffer four or more years and visit three or more doctors before obtaining a correct diagnosis.
- There is an urgent need to educate the public and health professionals to achieve earlier and more accurate diagnoses – and improved management – of lupus, in order to reduce and prevent its adverse effects, particularly among those communities most severely affected.

Statistics and Demographics

- Approximately 1.5 million Americans and more than five million individuals worldwide have a form of lupus.
- Ninety percent of the people with lupus are women. Eight of ten new cases of lupus develop among women of childbearing age; however, women of all ages as well as men and children develop the disease.
- Lupus is two to three times more common among African Americans, Hispanics/Latinos, Native Americans and Asians – a disparity that remains unexplained.
- There have been no new drugs approved by the U.S. Food and Drug Administration specifically for lupus in nearly 50 years; current treatments for the disease can lead to damaging side effects.

Causes of Lupus

- Researchers do not know the exact causes of lupus. However, lupus is NOT infectious.
- Researchers believe individuals with lupus have a genetic predisposition to the disease. However, it is also known that certain environmental factors play a role in triggering lupus. Environmental factors include: infections, antibiotics, ultraviolet light, extreme stress, and hormones. Hormonal factors may explain why lupus occurs more frequently in females than in males.
- The immune system normally makes proteins called antibodies to protect the body against viruses, bacteria, and other foreign materials. In lupus, the immune system loses its ability to tell the difference between foreign substances and its own cells and tissues. The immune system then makes antibodies directed against “self.”



There's More to **LUPUS** Than You Know

How Lupus Affects Major Organ Systems

(Attachment #2)

Lupus is a disease that causes inflammation to various parts of the body, including major organs such as the heart, lungs, kidneys, and brain. More than one-third of people with lupus will have organ-threatening disease that seriously affects the function of major organ systems.

Heart or Lung Involvement

- Pericarditis: inflammation of the lining surrounding the heart
- Myocarditis: inflammation of the tissue of the heart
- Coronary vasculitis: inflammation of blood vessels in the heart
- Pleuritis: inflammation of the sac surrounding the lungs
- Pneumonitis and/or fibrosis: inflammation and/or scarring of the lungs
- Pulmonary emboli: blood clots in the lungs

Brain and Nervous System Involvement

- Central nervous system vasculitis: inflammation of the blood vessels of the brain
- Cognitive dysfunction: confusion, memory impairment, fatigue, possibly due to decreased blood flow or inflammation in the brain
- Stroke: blood clots in the brain
- Seizures: can be caused by brain inflammation, scarring, strokes, or medications
- Myelitis: inflammation near the spinal cord
- Blood clots in spinal arteries

Kidney Involvement

- Lupus nephritis or glomerulonephritis: inflammation of the kidneys which leads to loss of protein, fluid retention, and edema (swelling)
- Severe cases of lupus nephritis can cause kidney failure requiring dialysis or transplantation

Blood and Blood Vessel Involvement

- Anemia: low red blood cell count
- Thrombocytopenia: low blood platelet count with risk for bleeding
- Leukopenia and neutropenia: low white blood cell count, from lupus or from treatment
- Thrombosis: blood clots, often associated with antiphospholipid antibodies
- Vasculitis: inflammation of the blood vessels



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Symptoms of Lupus (Attachment #3)

Although lupus can affect any part of the body, most people experience symptoms in only a limited number of organs. The table below lists the most common symptoms experienced by people with lupus. Symptoms can be acute (come on suddenly) or be mild and develop gradually over an extended period of time.

<u>Symptoms</u>	<u>Percentage of Occurrence</u>
Achy joints (arthralgia)	95%
Fever more than 100 degrees F	90%
Arthritis (swollen joints)	90%
Prolonged or extreme fatigue	81%
Skin rashes	74%
Anemia	71%
Kidney involvement	50%
Pain in the chest on deep breathing (pleurisy)	45%
Butterfly-shaped rash across the cheeks and nose	42%
Sun or light sensitivity (photosensitivity)	30%
Hair loss	27%
Abnormal blood clotting problems	20%
Fingers turning red and/or blue, or feeling numb or painful	17%
Seizures	15%
Mouth or nose ulcers	12%



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Could It Be Lupus?

(Attachment #4)

If you have had any symptoms like these, especially if you have had several, the Lupus Foundation of America suggests that you talk to your doctor about lupus. Early diagnosis and proper medical care are the best ways to manage lupus. For free information about lupus, call the Lupus Foundation of America at 1-888-38-LUPUS, or visit the LFA Website at www.lupus.org.

Brain and Nervous System

- Have you ever had a seizure or unexplained confusion that lasts for more than an hour?
- Have you had a fever over 100° F / 38° C for more than a few days?

Heart or Lungs

- Have you ever felt chest pain while taking deep breaths?

Kidneys

- Have you ever been told that you had protein in your urine?
- Have you ever had swelling in your legs and ankles on both sides at the same time?

Blood and Circulatory System

- Have you ever been told you have anemia, a low white cell count, or a low platelet count?
- Have your fingers and/or toes ever become red or blue, or felt numb or painful?
- Have you ever had a blood clot, heart attack, stroke, or miscarriage?

Eyes, Nose, and Mouth

- Have you ever had sores in your mouth or nose that lasted more than five days?

Muscles and Joints

- Have you ever had achy, painful and/or swollen joints for more than three months?
- Have you ever felt extreme fatigue or weakness for days or weeks, even after plenty of sleep?

Skin

- Have you ever had sores on your skin that would not heal?
- Has being in the sun ever given you a rash, but it is not a sunburn?
- Have you ever had redness or rash in the shape of a butterfly across your nose and cheeks?
- Have you ever had sudden, unexplained hair loss?



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Treatments for Lupus

(Attachment #5)

Medications

Although there is no cure for lupus, treatment can minimize symptoms, reduce inflammation, and maintain normal bodily functions for the vast majority of people with the disease. Medications often are prescribed for people with lupus, depending on which organs are involved, and the severity of involvement. Commonly prescribed medications include:

- **Non-Steroidal Anti-Inflammatory Drugs (NSAIDs)** – These drugs, such as aspirin and ibuprofen, are usually recommended for muscle and joint pain, and arthritis.
- **Acetaminophen** – A mild analgesic used for pain, such as Tylenol®.
- **Corticosteroids** – Synthetically produced corticosteroids, such as prednisone, are used to reduce inflammation and suppress activity of the immune system.
- **Antimalarials** – These drugs, such as Plaquenil®, are prescribed for skin and joint symptoms of lupus. It may take months before these drugs demonstrate a beneficial effect.
- **Immune modulating drugs** – These drugs, such as Imuran® and Cytoxan®, act in a similar manner to the corticosteroid drugs in that they suppress inflammation and tend to suppress the immune system.
- **Biologic drugs** – These drugs include agents that block the production of specific antibodies, like those against DNA, or act to suppress the manufacture of antibodies through other mechanisms.

Many of these medications are toxic and can cause other serious health problems over time. While potential new, safe and effective medications are in various stages of clinical development, it has been nearly 50 years since the U.S. Food and Drug Administration has approved a new therapy specifically for lupus.

Lifestyle Changes

In addition to taking prescribed medications, people with lupus can make lifestyle adjustments that help manage the disease and provide an improved sense of well-being. Preventive measures also can reduce the risk of flares.

- Avoidance of (excessive) sun exposure and the regular application of sunscreens can help prevent rashes and flares.
- Regular exercise helps prevent muscle weakness and fatigue.
- Immunization protects against specific infections; however, live virus vaccines are not recommended for people with lupus.
- Maintaining a healthy lifestyle is important – get plenty of rest, reduce stress, eat a balanced diet, and quit smoking.



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About the Lupus Foundation of America

The Lupus Foundation of America is the foremost national nonprofit voluntary health organization dedicated to finding the causes of and cure for lupus and providing support, services, and hope to all people affected by lupus. Research and education are at the heart of the LFA's programs. The LFA has a nationwide network of nearly 300 chapters and support groups to help people with lupus, their families, and health professionals.

The LFA energetically pursues its mission through programs of research, education, support, and advocacy in order to:

- Provide direct financial support to lupus researchers through LFA's research program;
- Greatly increase public and private sector funding of lupus research;
- Heighten public awareness of the causes and consequences of lupus;
- Educate physicians and other health professionals about the latest scientific findings on lupus;
- Support individuals with lupus, their families, and health professionals.