

Help Us Solve  
The Cruel Mystery  
**LUPUS**<sup>™</sup>  
FOUNDATION OF AMERICA  
INDIANA CHAPTER

# **Lupus: Deciphering the Clues**

# Vision, Mission

- Vision:

A world without lupus. The organization will advance the science and medicine of lupus to find a cure and improve the quality of life for all people affected by lupus.

- Mission:

The Lupus Foundation of America is dedicated to improving the quality of life for all people affected by lupus through programs of research, education and advocacy

80% of the public know little or nothing about lupus

Most at risk are least familiar with lupus

Lupus Awareness

Low awareness results in late diagnosis, increased morbidity, and increased costs

Average of 4 years and 3 doctor visits to get a correct lupus diagnosis

# What is Lupus?

- Lupus is a chronic autoimmune disease that can damage any part of the body.
- With autoimmune diseases, the body cannot tell the difference between “invaders” (i.e., bacteria and viruses) and the body’s own healthy tissues.

# Lupus is...

- Different for each person
- A disease that ranges from mild to life threatening
- Not curable
- Symptoms of the disease may increase (flare), decrease, or become inactive (remission)

# Lupus is Not...

- Contagious or transmittable
- Like or related to cancer
- Like or related to HIV (Human Immune Deficiency Virus) or AIDS (Acquired Immune Deficiency Syndrome)

# What Causes Lupus?

- Scientists continue to look for the definitive cause(s) of lupus, it is clear that there is a genetic link
- While a person's genes may increase the chance that they will develop lupus, it takes some kind of environmental trigger to set off the illness
  - Exposure to ultraviolet radiation (sunlight)
  - Female Hormones
  - Exposure to infections
  - Physical and emotional stress

# Who Gets Lupus?

- Approximately 1.5 million Americans have lupus
- More than 16,000 people in the U.S. develop lupus each year
- Women are approximately 10 times more likely than men to have lupus
- Strikes mostly women in childbearing years (15-44)
- Women of color are 2-3 times more likely to develop lupus
- Children, teenagers and men can develop lupus, too



# Lupus in the Hispanic & African American Communities

- **L**upus in **M**inorities: **N**ature versus Nurture (LUMINA) studies show that Hispanic and African American lupus patients tend to:
  - Have more severe disease overall
  - Develop lupus earlier in life
  - Experience greater disease activity at the time of diagnosis (including kidney problems)
  - Have more neurological problems such as seizures, hemorrhage (internal bleeding) and stroke.

**Central and Peripheral Nervous System**

Seizures, Psychosis, Headaches,  
Cognitive Dysfunction,  
Neuropathies, Depression,  
Low Grade Fever

**Eyes and Mucous Membranes**

Ulcers in the Eyes, Nose,  
Mouth or Vagina,  
Sjögren's Syndrome

**Heart, Lungs**

Pericarditis, Myocarditis,  
Endocarditis, Pleuritis,  
Pneumonitis

**Gastrointestinal**

Nausea, Vomiting, Diarrhea,  
Weight Changes

**Kidneys**

Edema, Hypertension,  
Proteinuria, Cell Casts,  
Renal Failure

**Reproductive System**

Pregnancy Complications,  
Miscarriages,  
Menstrual Cycle Irregularities

**Musculoskeletal**

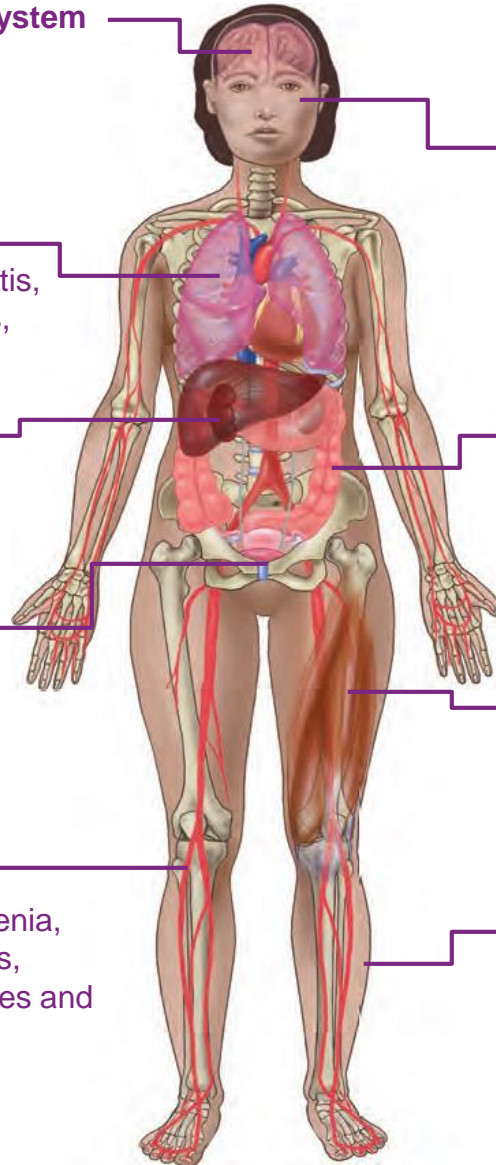
Extreme Fatigue, Arthralgia,  
Myalgia, Arthritis, Myositis

**Blood**

Anemia, Thrombocytopenia,  
Leukopenia, Thrombosis,  
Circulating Autoantibodies and  
Immune Complexes

**Skin**

Butterfly Rash, Cutaneous  
Lesions, Photosensitivity,  
Alopecia, Vasculitis,  
Raynaud's Phenomenon



# Economic Impact of Lupus

- The annual cost of medical treatment ranges from \$12,000 to \$62,000, depending on the severity of lupus [1]
- Many people with lupus receive their health care through a government-sponsored program such as Medicare or Medicaid.
- Annually, lupus patients had **3** times more doctor's visits and used **13** times more outpatient services than those without lupus [2]

# What are the Different Forms of Lupus?

- Systemic Lupus Erythematosus (SLE)
- Cutaneous Lupus Erythematosus
- Drug-Induced Lupus
- Neonatal Lupus

# Systemic Lupus Erythematosus (SLE)

- The most common form of lupus
- Various parts of the body are affected
- Common symptoms include fatigue, hair loss, sensitivity to the sun, painful and swollen joints, unexplained fever, skin rashes, kidney problems

# Cutaneous Lupus Erythematosus

- Can be limited to the skin or a component of systemic lupus
- Symptoms may include rashes/lesions, hair loss, vasculitis, ulcers, photosensitivity
- Three major subsets of cutaneous lupus:
  - Malar (butterfly) rash is present in about 1/3 of those with systemic lupus
  - Discoid lupus accounts for approximately 10% of all lupus cases and it occurs in 20% of those with systemic lupus
    - Approximately 10% of people with discoid lupus later develop systemic lupus
  - Subacute cutaneous lupus makes up 10% of the overall lupus diagnosis. About 50% of the time, these individuals will meet the criteria for systemic lupus.

# Examples of Cutaneous Lupus



Malar Rash  
or  
"butterfly rash"



Image Provided by: Dr. Victoria Werth

Subacute Cutaneous  
Lupus



Image Provided by: Dr. Victoria Werth

Discoid Lupus  
Erythematosus

# Drug-Induced Lupus

- A side effect of long-term use of certain medications
- At least 46 drugs can cause drug-induced lupus
- Drugs most commonly connected with drug-induced lupus are:
  - Hydralazine ( Apresoline ®)
  - Quinidine (Quiniglute ®)
  - Procainamide (Pronestyl ®)
- Symptoms include joint and muscle pain, arthritis, flu-like symptoms, and inflammation of the heart & lungs
- When medications are stopped, symptoms resolve (usually within six months)



# Neonatal Lupus

- A rare condition
- Affects infants of women who have lupus
- Caused by antibodies from the mother acting upon the infant in the womb
- Most infants of mothers with lupus are entirely healthy

# How is Lupus Treated?

- There are many therapies used to treat lupus
- Treatment will vary depending on the organ systems involved in your disease
- FDA Approved Therapies for Lupus:
  - **Corticosteroids:** prednisone, prednisolone, methylprednisolone, and hydrocortisone
  - **Antimalarials:** Plaquenil®, Chloroquine (Aralen®), Quinacrine
  - **Monoclonal antibodies:** BENLYSTA® (Belimumab)
  - **Immunosuppressive (Immune Modulators):** Cyclophosphamide (Cytoxan®), Methotrexate (Rheumatrex™), Azathioprine (Imuran®)
  - **Anti-inflammatories:** Aspirin, NSAIDs, Acetaminophen
  - **Anticoagulants:** heparin (Calciparine®, Liquaemin®) and warfarin (Coumadin®)

# Lifestyle Considerations

- Fatigue & Rest
- Work
- Exercise
- Diet and nutrition
- Smoking
- Sensitivity to light

# On the Horizon

- There has been enormous progress in recent years in understanding the biology of lupus
- Numerous new approaches to treatment are under development and/or investigation
- Increased knowledge about lupus has improved management of the disease.
- Today, people with lupus are leading healthier lives and living longer than ever before.

# LFA National Office Resources

- Visit us at [www.lupus.org](http://www.lupus.org)
- LFA Health Educator available to answer questions by email or phone (**800-558-0121**)
- Online resources and print materials
- Find a local chapter and support group
- Chapters and support groups can also help you find local community health resources
- Ways to get involved (Walks, Advocacy, Facebook, Twitter, etc.)

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Thank You

Help Us Solve  
The Cruel Mystery

**LUPUS**<sup>TM</sup>

FOUNDATION OF AMERICA

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2. Kan, H. J., Song, X., Johnson, B. H., Bechtel, B., O'sullivan, D., & Molta, C. T. (2013). Healthcare Utilization and Costs of Systemic Lupus Erythematosus in Medicaid. *BioMed Research International*, 2013, 1-8.
3. Chertow, G. M. (1999). Issues in Evaluating the Cost-Effectiveness of Dialysis. *Seminars in Dialysis*, 12(5), 355-358.
4. Rosenthal, J. A., Lu, X., & Cram, P. (2013). Availability of Consumer Prices From US Hospitals for a Common Surgical Procedure. *JAMA Internal Medicine*, 173(6), 427.