
LUPUS

BRIDGING THE GAP BETWEEN SYMPTOM & DIAGNOSIS



WHAT IS LUPUS?

- An autoimmune disease that can affect the joints, skin, heart, lungs, nervous system, blood, kidneys and other organs.
- Types of lupus:
 - Systemic Lupus Erythematosus (SLE) – the most common type of lupus.
 - Cutaneous Lupus – involves the skin only, appearing as rashes and lesions.
 - Drug-induced – a lupus-like reaction caused by certain prescriptions.
 - Neonatal – a condition caused when the antibodies of a mother with lupus act upon an infant while in the womb.
- There is currently no known cure for lupus, but the disease and its symptoms can be managed.

HOW COMMON IS LUPUS?

- Lupus affects more people than multiple sclerosis, cystic fibrosis, sickle cell anemia, cerebral palsy and AIDS – **combined**.
- It remains the least-known major disease of our day.
- 23.5 million Americans suffer from autoimmune disease and that number is growing, according to the National Institutes of Health.
- 1 in 3 lupus patients have multiple autoimmune diseases.
- Lupus takes an average of **6 years** to be diagnosed.

WHO GETS LUPUS?

- 90% of those who have lupus are women. Most are diagnosed between the ages of 15 and 44.
- Men and children get lupus, too.
- Those of African descent are 3 times more likely to have lupus, to display symptoms at a younger age and to have more severe, complex cases.
- Those of Asian, Hispanic or Native American descent are 2 to 3 times more likely to have lupus.
- Poverty exacerbates the disease.

COMMON SYMPTOMS OF LUPUS

- Extreme fatigue
- Low grade fever
- Achy joints
- Mouth sores
- Hair loss
- Pain when breathing deeply
- Rash
- Dry eyes and mouth (Sjögren's Phenomenon)
- Sensitivity to cold (Raynaud's Syndrome)
- Anemia
- Brain Fog

LUPUS AND THE SKIN

- Exposure to the sun can cause a significant skin rash in those with lupus. It is commonly referred to as a butterfly rash.



LUPUS AND THE SKIN

- Mucosal sores may appear on the hard palate of the mouth.



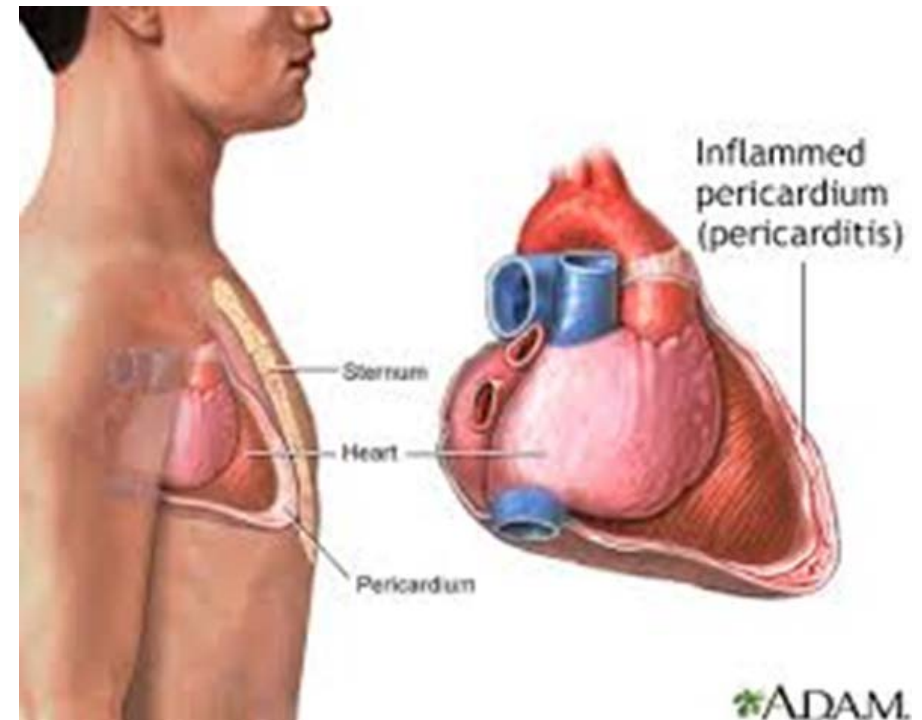
LUPUS AND THE JOINTS

- Joints may be warm, stiff, tender and swollen.



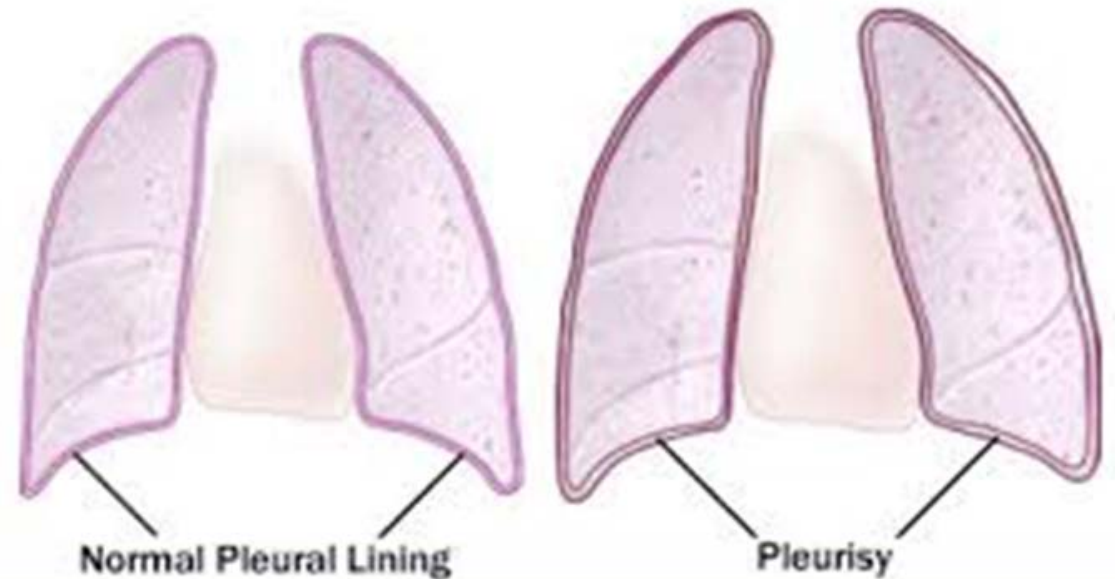
LUPUS AND THE HEART

- Pericarditis, the inflammation of the outside lining of the heart, may cause chest pain, tightness, or shortness of breath.



LUPUS AND THE LUNGS

- Pleurisy, inflammation of the lining of the lungs, can cause sharp pain when a lupus patient takes a deep breath.



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LUPUS AND THE KIDNEYS

- Lupus nephritis, which attacks the kidneys, is usually found through blood tests, urine tests and a kidney biopsy.
- Patients may also develop edema or severe swelling of various body parts.



LUPUS AND THE NERVOUS SYSTEM

- Depression can be a symptom of the disease; it can also be a side effect of treatment (steroids) and inability to get restorative sleep.
- Cognitive change, commonly called “lupus fog”, can cause words to be confused or cause someone to forget what they are saying in the middle of a conversation. Lupus fog is episodic and does go away.

LUPUS AND THE BLOOD VESSELS

- Raynaud's phenomenon is an extreme sensitivity to cold that can affect the fingers, toes and nose. This can happen in air conditioning, outside, even in the refrigerator section of a supermarket.



BARRIERS TO CARE

- Delayed diagnosis and treatment
 - Mirrors other diseases
 - Not enough rheumatologists
 - Lupus does not follow a standard path of progression; no two cases are the same
 - Treatment of the disease is primarily “off-label”

BARRIERS TO CARE

Continued...

- Psychological, socio-economic and cultural conditions
 - Patients rarely “look” sick, causing others to trivialize or question their pain and fatigue
 - Delayed diagnosis causes anxiety and self-doubt
 - Poverty exacerbates the disease
 - In many cultures, women are honored for and encouraged to be selfless, causing them to put themselves last and delay medical attention

BARRIERS TO CARE

Continued...

- Inadequate access to information and support
 - Rural areas have too few rheumatologists and, even in urban areas, wait lists can be more than a year
 - Community-based meetings are most often held in more populated areas
 - Physical and economic limitations

BRIDGING THE GAP: PROGRAMS OF EDUCATION AND EMPOWERMENT

- Information and links to resources
 - Publications about lupus and related diseases Brochures for distribution by health care providers
 - Brochures to help raise awareness among community service providers
 - Physician lists by location

BRIDGING THE GAP: PROGRAMS OF EDUCATION AND EMPOWERMENT

Continued...

- Lupus Education & Advocacy Network (*LEAN FORWARD*) programs
 - **NEW!** Fully-accessible monthly videos on important, relevant topics
 - Community based meetings for lupus warriors, loved ones and caregivers
 - Regional symposiums featuring subject matter experts and opportunities for Q&A
- Lupie Love Notes a **NEW!** program that delivers daily messages of inspiration
- Quarterly news updates

BRIDGING THE GAP: PROGRAMS OF EDUCATION AND EMPOWERMENT

Continued...

- Presentations to professional and community groups
- Community-building special events

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illuminating lupus, lifting community