

# LIVING WITH SYSTEMIC LUPUS ERYTHEMATOSUS

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## Agenda

- What is lupus
- Who is affected
- Causes of lupus
- Symptoms and organ involvement
- Diagnosis
- Treatment
- Pregnancy and lupus
- Resources
- QUESTIONS

## Definition

- Chronic autoimmune disease
- The body's immune system starts attacking itself
- Can affect most organs and tissues in the body
  - Brain, lungs, heart, joints, skin, blood, kidneys

## The Types of Lupus

- Systemic lupus erythematosus (SLE or lupus)
  - Any organ
- Cutaneous/discoid/skin lupus
  - Skin only
- Drug-induced
  - Medications cause
- Mixed connective tissue disease
  - Associated with other autoimmune diseases
- Neonatal lupus
  - Affect infants of women with lupus



## Who Treats Lupus?



- Systemic Lupus Erythematosus – Rheumatologist
- Cutaneous lupus – Dermatologist
- Other specialists
  - Nephrologist – kidney disease
  - Cardiologist – heart problems
  - Neurologist – nervous system problems
  - Perinatologist – high risk pregnancies

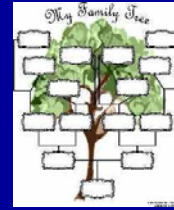


## Facts About Lupus



- 1.5 million people have lupus
- More than 16,000 new cases reported in the US each year
- Women in childbearing years
  - 9 of 10 lupus patients are women
- People of all races and ethnic groups can develop lupus
- Women of color 2 -3 times more likely

## Causes



- Not known
- Possibly hormones, genetics and environment
- Sex hormone estrogen
  - Women produce more than men
- Genetics
  - Lupus or other autoimmune diseases like rheumatoid arthritis in the family
  - Greater in ethnic groups – African, Asian, Hispanic/Latino, Native American or Pacific Island descent



## Causes cont.



### ■ Environment

- Genes increase the chance of lupus, but some environmental trigger most likely is needed
  - Ultraviolet or fluorescent light
  - Sulfa drugs and tetracycline (more sensitive to the sun)
  - Infection, colds, exhaustion, injury, emotional stress, physical stress (accident, pregnancy, surgery)

## Causes cont.

**Not contagious!!!!!!**

## Symptoms

- Fatigue
- Painful or swollen joints
- Anemia
- Fever
- Headaches
- Swelling in the feet, legs, hands and/or around the eyes
- Pain in chest on deep breathing (pleurisy)
- Muscle pain
- Butterfly-shaped rash across the cheeks and nose
- Hair loss
- Sensitivity to the sun
- Blood clotting problems
- Ulcers in the mouth/nose
- Fingers turning red, white and blue (Raynaud's phenomenon)

## Frequency of Symptoms

Symptoms	Percent at Onset	Percent at Anytime
Fatigue	50	74-100
Fever	36	40-80+
Joints	62-67	83-95
Skin	73	80-91
Kidneys	16-38	34-73
Heart	15	20-46
Lungs	2-12	24-98
Gastrointestinal	18	38-44
Brain	12-21	25-75

Von Feldt JM, Postgrad Med 1995; 97:79

## Arthritis/Joint pain

- Joint symptoms in over 90% of patients at some time
- Can move from joint to joint
- Hands are often involved
- Rarely deforming



## Skin Manifestations

- Butterfly rash
- Discoid lesions
- Hair loss (alopecia)
- Oral and nasal ulcers

## Skin Manifestations



Malar rash

Discoid lupus



Alopecia

# Skin Manifestations

Photosensitivity



Oral Ulcer



# Raynaud's Phenomenon

- Cold-induced color changes of the fingers or toes





## Kidney Involvement

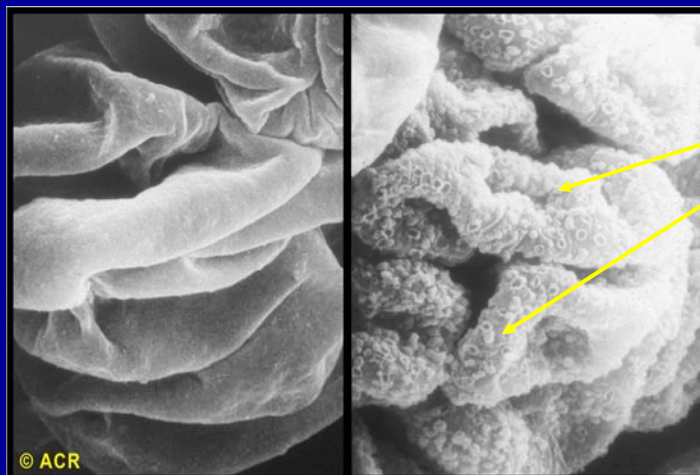


- Lupus nephritis - Inflammation in the glomerulus (filters)
  - Difficulty filtering waste from the bloodstream
- Nephrotic syndrome
  - Kidneys may leak protein from the blood into the urine
  - Water retention and swelling in the lower legs and feet
  - Without treatment the kidneys can be permanently scarred and dialysis may be required
- Treatments exist to prevent or minimize the damage to the kidney

## Kidney Involvement

Normal

SLE



Immune  
complexes

© ACR

## Serositis

- Inflammation of the serous tissues of the body. The serous tissues line the lungs (pleura), heart (pericardium), and the inner lining of the abdomen (peritoneum) and organs within

## Digestive Tract

- Medications like prednisone and NSAIDs (Ibuprofen) can cause stomach upset and stomach ulcers
- Lupus can cause inflammation of the pancreas (pancreatitis), the lining of the abdomen (peritonitis) or the large intestine (colitis)
  - Severe abdominal pain, nausea, and vomiting

## Digestive Tract



Halos – inflammation of the intestines

## Lungs

### ■ Pleurisy

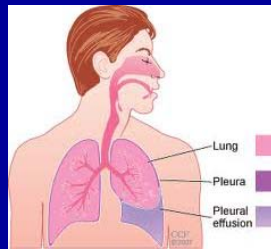
- Chest pain when taking a deep breath
- Due to inflammation of the lining covering the lungs and inside of the chest



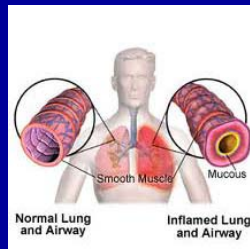
Inflammation

# Lungs

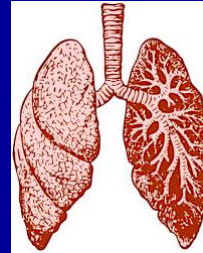
- Shortness of breath
  - Pleural effusion – fluid in the space around the lungs preventing the lungs from expanding
  - Pneumonitis – inflammation of the air sacs of the lung
  - Interstitial lung disease – scarring or dysfunction of the tissues between the air sacs



Pleural effusion



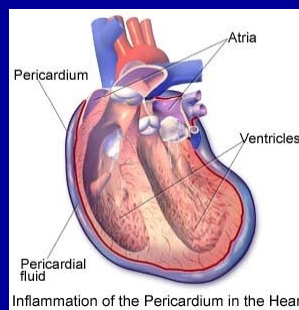
Pneumonitis



Interstitial lung disease

# Heart

- Shortness of breath due to heart valve disease
- Chest pain due to inflammation around the heart – pericarditis
- Chest pain with exercise
  - Increased risk for heart disease like a heart attack



Inflammation of the Pericardium in the Heart

## Nervous System Central and Peripheral

- Difficulty concentrating
- Memory loss or confusion
- Depression/Anxiety
- Psychosis
- Seizures
- Meningitis
- Cerebritis
- Peripheral neuropathy – pain or numbness in the hands or feet

## Hematologic (Blood) Disorder



- Anemia (low red blood cells)
  - Hemolytic
- Leukopenia (low white blood cells)
  - Lymphopenia
- Thrombocytopenia (low platelets)
  - Idiopathic thrombocytopenic purpura (ITP)
- Antiphospholipid antibodies

## Cardiovascular Disease

- Increased risk for heart attacks and strokes at a younger age
- Know the signs and symptoms
- Seek immediate medical attention

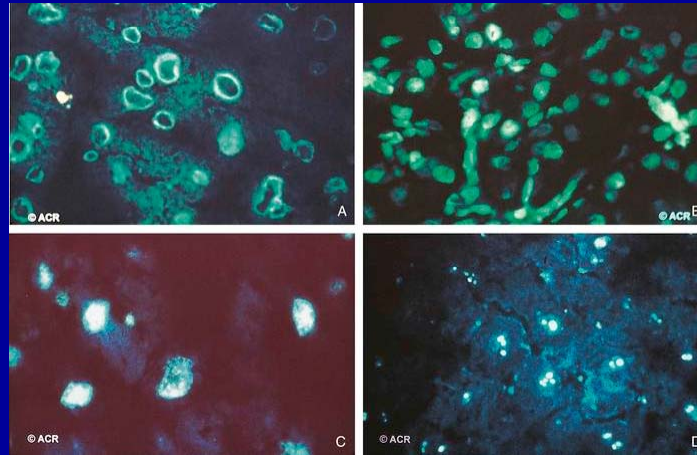


## Diagnosis

- No single test
- Health history and current symptoms
- Family history
- What the doctor sees on exam
- Lab tests



## Antinuclear Antibody (ANA)



## Diagnosis 11 Common Criteria

- Malar rash
- Discoid rash
- Photosensitivity
- Oral ulcers
- Arthritis
- Serositis
- Renal disorder
- Neurologic disorder
- Hematologic disorder
- Immunologic disorder
- Antinuclear antibody

VS.

SLICC Criteria

## Treatment Strategy

- Individual treatment plans are implemented for each patient and may alter during the course of the disease
- Prognosis has improved with earlier detection of disease and aggressive treatment of renal disease



## Medications

- Goal - Suppress the immune system and reduce inflammation
- Glucocorticoids
  - Prednisone
- Lupus specific therapy
  - Antimalarials
    - Hydroxychloroquine
  - Monoclonal antibody
    - Belimumab
- Nonspecific therapy
  - Immunosuppressives
    - Azathioprine, methotrexate, mycophenolate, cyclophosphamide
- In development



## Medication Treatments

Don't stop your medications  
without talking to your doctor first!!!

## Non-Medical Treatments

- Educate yourself on lupus
- Medication precautions – herbals, supplements
- Diet and nutrition
  - No special diet
  - Well-balanced - low in fat, high in fruits, vegetables and grains
- Sun protection
- Exercise
- Rest
- Stop smoking
- Support system





## Pregnancy and Lupus

- Plan with your physician
  - You should not get pregnant on certain medications because of the increased risk for fetal abnormalities or miscarriage
    - Off some medications at least 3 months so they can clear your system
  - Certain medications cannot be taken when breastfeeding
- Avoid becoming pregnant during lupus flares
  - High risk of miscarriage
- Chances of an uncomplicated pregnancy and healthy newborn are improved by waiting until lupus is controlled for 6 months

## Pregnancy and Lupus



Most infants are healthy



# QUESTIONS?

## Resources for Lupus Patients

- [www.lupus.org](http://www.lupus.org) (LFA National Office)
- [www.arthritis.org](http://www.arthritis.org)
- [www.LupusResearchInstitute.org](http://www.LupusResearchInstitute.org)
- [www.niams.nih.gov/Health\\_Info/Lupus](http://www.niams.nih.gov/Health_Info/Lupus)