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

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

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

Normal SLE

Immune complexes
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
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

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
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

Most infants are healthy
QUESTIONS?

Resources for Lupus Patients

- www.lupus.org (LFA National Office)
- www.arthritis.org
- www.LupusResearchInstitute.org
- www.niams.nih.gov/Health_Info/Lupus