UNDERSTANDING THE MYSTERY OF LUPUS

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GOALS OF THIS TALK: ANSWER THESE QUESTIONS

1. What is lupus?
2. Who can get lupus?
3. What causes lupus?
4. How is lupus diagnosed?
5. How is lupus treated?
6. Where can I learn more?
WHAT IS LUPUS?

Lupus = Lupus Erythematosus

- “Lupus” means wolf in Latin
- “Erythematous” means redness
WHAT IS LUPUS?

• There are 4 different types of lupus:
  • Systemic Lupus Erythematosus (AKA SLE)
  • Cutaneous Lupus
  • Drug-Induced Lupus
  • Neonatal Lupus
WHAT IS LUPUS?

**Chronic, systemic autoimmune disease**

- Chronic - Symptoms can last many years
- Systemic - Can involve the entire body as well as the internal organs and skin
- Autoimmune - Parts of the immune system attack the body’s own tissues
WHAT IS LUPUS?

- The severity of lupus can vary from person to person
- Can have periods of active disease/flares and other times with remission
- Can cause skin rashes and damage internal organs
- Can have a big impact on quality of life
WHAT LUPUS IS NOT

- Lupus is NOT contagious
  - People with lupus cannot spread it to others or catch it from others
- Lupus is NOT an infection
  - It is not related to HIV in any way
  - It cannot be cured with antibiotics
WHAT LUPUS IS NOT

- Lupus is NOT related to cancer
  - (Although some treatments are similar)
- Lupus is NOT caused by something you eat
  - There is no “elimination diet” proven to treat lupus
HOW COMMON IS LUPUS?

- Rare disease - Lupus affects around 5 out of 100,000 people
- Lupus affects 1.5 million Americans and over 5 million people worldwide
- More common in certain racial/ethnic groups
- Much more common in women - 9:1 ratio of women to men
WHO CAN GET LUPUS?

- Anyone can be affected by lupus
WHO CAN GET LUPUS?

- More common in African Americans and Hispanic people than in Asian and Caucasian people

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Proportion of young black women impacted by lupus.

www.resources.lupus.org
WHO CAN GET LUPUS?

- Usually starts between ages 15-45
WHAT ARE THE SYMPTOMS OF LUPUS?

• Symptoms vary from person to person
• Can affect any organ of the body

Body System Affected By SLE
- Nervous (Central)
- Ophthalmologic
- Oral
- Dermatologic
- Cardiopulmonary
- Renal
- Gastrointestinal
- Reproductive
- Hematologic
- Musculoskeletal
LUPUS IS SOMETIMES VISIBLE ON THE OUTSIDE
LUPUS IS SOMETIMES ONLY HIDDEN INSIDE
SYMPTOMS/EFFECTS OF LUPUS

- Skin
  - Butterfly rash
  - Discoid rash
- Hair loss
- Sores in the mouth
SYMPTOMS/EFFECTS OF LUPUS

- Foggy thinking
- Seizures
- Vision problems
SYMPTOMS/EFFECTS OF LUPUS

- Joint pains
- Muscle weakness
- Liver inflammation
- Inflammation of lining of lungs and heart
- Blood clots
- Kidney damage
KIDNEY DAMAGE IN LUPUS

• Up to 50% of patients with systemic lupus erythematosus develop lupus nephritis

• Kidneys are important to filter our blood and regulate fluids in the body

• Lupus can damage the kidneys when the immune system attacks the kidneys
KIDNEY DAMAGE IN LUPUS

• Signs of kidney involvement from lupus:
  • Swelling of the ankles or belly
  • Elevated blood pressure
  • There may not be any symptoms - needs to be screened by a doctor regularly

• If not treated, this can cause permanent kidney failure
SYMPTOMS/EFFECTS OF LUPUS

- Pregnancy complications
- Low blood counts
  - Anemia
  - Bleeding
  - Infections
- Most patients also have **fatigue** and **fevers**
OTHER HEALTH CONCERNS FOR PEOPLE WITH LUPUS

• Cardiovascular disease
  • People with lupus have a higher risk of heart attacks and stroke

• Infection

• Osteoporosis

• Depression
WHAT CAUSES LUPUS?

Combination of **genetic** and **environmental** factors

- There is not one gene that causes lupus- **at least 50** different genes increase risk!
- 20% of people with lupus also have a family member with the disease
WHAT CAUSES LUPUS?

Combination of genetic and environmental factors

- Environmental triggers
  - Sunlight
  - Pregnancy
  - Infections
WHAT CAUSES LUPUS?

• Lupus is an autoimmune disease
• Normally our immune system fights infection
• In Lupus, the immune system attacks itself
WHAT CAUSES LUPUS?

• The immune system acts abnormally in Lupus
• Usually the immune system protects us against infection
• Normally we have antibodies that fight these infections
• In lupus, the body forms **auto**antibodies
• Lupus targets the own body’s own cells as if they were viruses
WHAT CAUSES LUPUS?

• The most common autoantibody in lupus is the Anti-Nuclear Antibody, also caused the “ANA”

• Autoantibodies lead to inflammation that damages the tissues including the skin and/or internal organs
HOW IS LUPUS DIAGNOSED?

• Difficult to diagnosis since it is so complex and variable
  • Sometimes called the “great imitator”
  • On average, it takes 6 years to obtain a diagnosis of lupus

• Different people with lupus often have different signs and symptoms

• Some of the symptoms can be caused by other problems too
  • Fatigue, headache, body aches
HOW IS LUPUS DIAGNOSED?

• Evaluation by a Rheumatologist or other specialist physician trained to treat lupus
• Combination of symptoms, blood tests, and other factors
• There is no one blood test that makes the diagnosis of lupus
HOW IS LUPUS DIAGNOSED?

• Blood tests:
  ▪ Certain auto-antibodies
    ▪ ANA- Antinuclear Antibody- positive in almost 100% of patients
    ▪ Anti-DNA, anti-RNP, anti-Smith, anti-Ro, anti-La
    ▪ Antiphospholipid antibodies
  ▪ Blood cell counts
  ▪ Tests of kidney function
HOW IS LUPUS TREATED?

- Healthy lifestyle habits are very important
  - Exercise regularly
  - Eat a healthy diet with fruits, vegetables, lean meats, etc.
  - Get enough sleep
  - Manage stress
HOW IS LUPUS TREATED?

- Healthy lifestyle habits are very important
  - Avoid smoking tobacco
  - People with lupus who smoke are more likely to have disease flares
  - People with lupus who smoke are more likely to have heart disease and strokes
HOW IS LUPUS TREATED?

Avoid excess sun-exposure

- Wear sunscreen and protective clothing
- Sun exposure can cause lupus flares including rashes and overall disease flares
HOW IS LUPUS TREATED?

• Medications prescribed by a Rheumatologist or other specialist
• Medications can treat active inflammation caused by lupus
• Medications can prevent permanent organ damage from lupus, such as kidney failure and the need for dialysis
HOW IS LUPUS TREATED?

- Choice of medication depends on severity of symptoms
  - Prednisone (AKA steroids)
  - Hydroxychloroquine (AKA Plaquenil)- for most patients
  - Immunosuppressant medications
HOW IS LUPUS TREATED?

• “Biologic” medications that target certain parts of the immune system
  • Belimumab
• New medications are on the horizon!
  • Many ongoing clinical trials
WHAT ELSE IS IMPORTANT FOR PEOPLE WITH LUPUS?

• Developing a strong support system can be helpful
  • Educating friends, relatives, and coworkers about lupus can help them understand what you are going through

• Support groups can be helpful for some individuals to connect with others and share experiences
WHERE CAN I LEARN MORE?

Lupus Foundation of America:
www.resources.lupus.org

American College of Rheumatology:
www.rheumatology.org/I-Am-A/Patient-Caregiver/Diseases-Conditions/Lupus
RESOURCES FOR PATIENTS WITH LUPUS

Mass General Lupus Program:
617-726-7938
