

Help Us Solve
The Cruel Mystery

LUPUSTM

FOUNDATION OF AMERICA

Living With Lupus

October 15TH, 2016 Georgia Lupus Empowerment Summit
WAMBUI MACHUA, MD



P

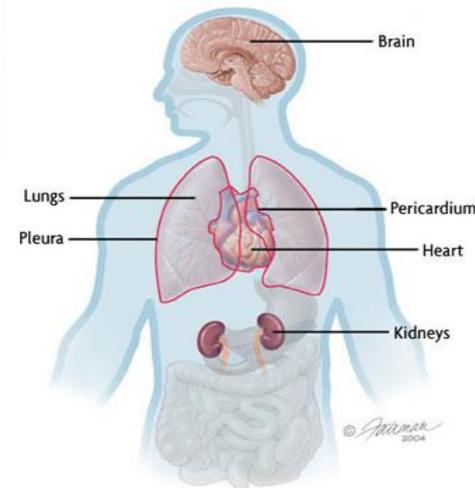
LUPUS



- Latin for “wolf”
- 13th century physician – Rogerius used the word to describe erosive fascial lesions reminiscent of a wolf’s bite



LUPUS



DEFINITION

- **A chronic inflammatory disease that occurs when your body’s immune system attacks your own tissue and organs**
- **Organs: joints, skin, kidneys, blood cells, heart, lungs and rarely brain**

FACT:

LUPUS is an unpredictable and
misunderstood

AUTOIMMUNE DISEASE

that ravages different

parts of the body.



LUPUS WARNING!

- **Not everything we say today applies to you if you have lupus nor to your family members or your friends if they have lupus**
- **Each person's lupus is different and specific to that person**
- **You are not just a patient; you are a normal person who happens to have lupus**

Who Gets Lupus?

- **Approximately 1.5 million Americans have lupus**
- **16,000 Americans develop lupus each year**
- **Women are approximately 10 times more likely than men to have lupus**

Who Gets Lupus?

- **Often affects women of child bearing age**
- **African American, Hispanic/Latino, Asians, Native Americans are 2-3 times more likely than Caucasian women to be affected**
- **Children, teenagers, men, and the elderly develop lupus**

FACT:

90% of **LUPUS** patients are

WOMEN

— aged 18-45, —

lupus also affects
men, children and

women of all ages.



FACT:

African Americans, Hispanics/Latinas, Asians, Pacific Islanders, and Native Americans, are diagnosed

_____ with **LUPUS** _____



2 to 3 TIMES

more frequently than **Caucasians**; however, lupus

affects people of all **races** and **ethnicities**.

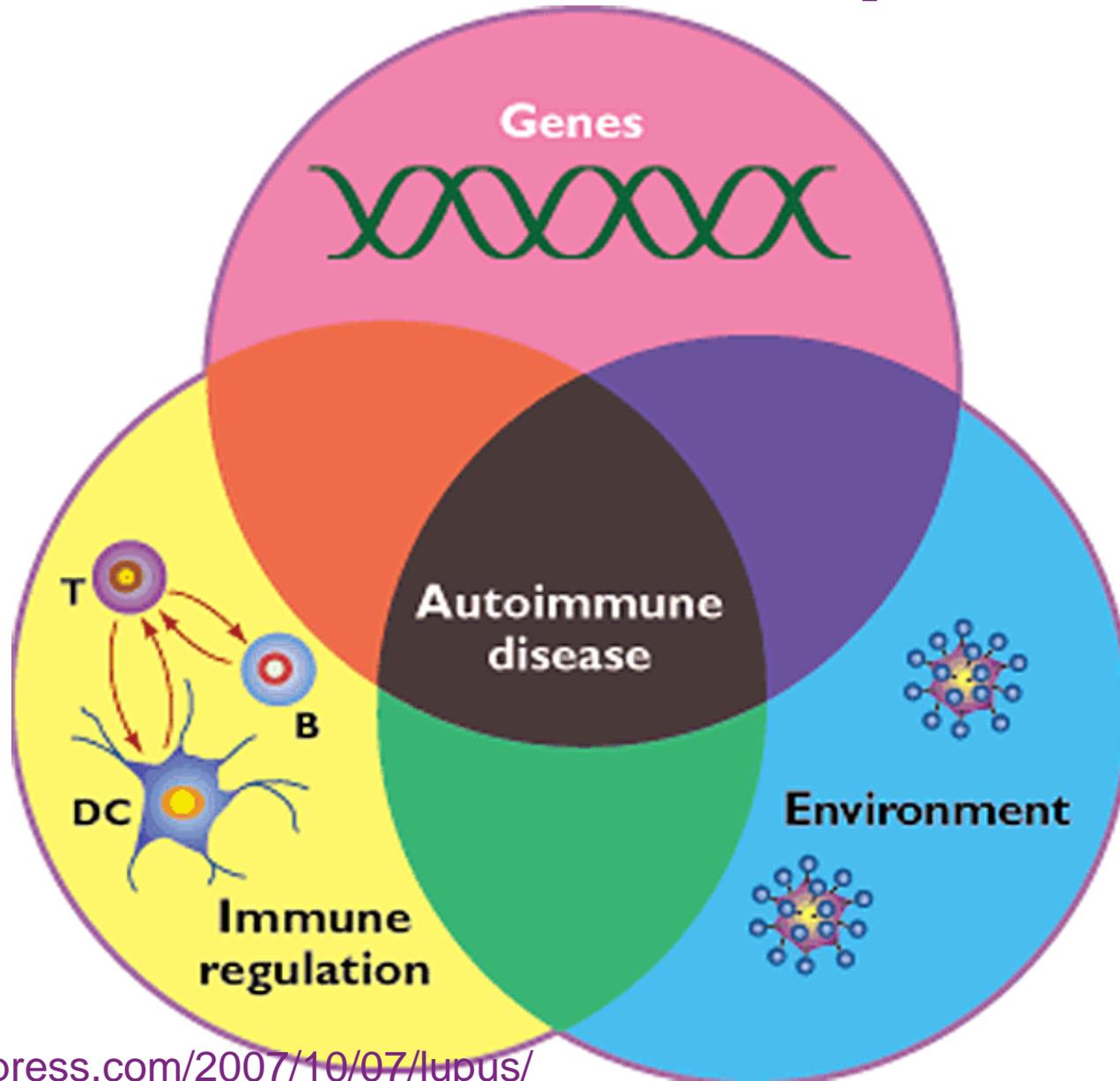
What Causes Lupus?

- **Scientists are still looking for the definitive cause(s) of lupus**
- **Gender**
- **Environmental factors may play a role in triggering lupus**

What Causes Lupus?

- **Genetic predisposition also may impact a person's risk for developing lupus**
- **It is likely that a combination of environmental genetic, and other possible factors trigger lupus**

What Causes Lupus?



FACT:

In **LUPUS**, something goes wrong with the

immune system,

which is the part of the body that

— *fights off* — **viruses,**

bacteria, and germs.

The result is the production of autoantibodies that cause

INFLAMMATION.



FACT:

Sensitivity to *ultraviolet light* (present in both sunlight and artificial light) affects as many as

2/3 of individuals with **LUPUS**

and may cause

fever, debilitating fatigue, joint pain, rashes and other symptoms.



What are the Different Types of Lupus?

- **Systemic Lupus Erythematosus (SLE)**
- **Cutaneous Lupus Erythematosus (Discoid or CLE)**
- **Drug-Induced Lupus (DILE)**
- **Drug induced, Biologic medication induced Lupus-like SLE**
- **Neonatal Lupus in newborn**

FACT:

Many symptoms of **LUPUS** imitate those of other *illnesses*, and can come and go over time, making *diagnosis difficult*.

— Consequently, it may take —

3 to **5**

— years or more to diagnose *lupus*. —

Things that can activate lupus

- **UV Light**
 - **Use sunscreen**
 - **At least SPF 60**
 - **Need UVA/UVB protection**
 - **Reapply 2-3 times if exposed to water/ very sunny**
 - **Wear sun protective clothing**
 - **Wide-brimmed hat**
- **Avoid substances that can cause flares**
 - **Echinacea- herbal for colds**
 - **Co Q 10**
 - **Melatonin- herbal for sleep**
 - **Alfalfa sprouts**
 - **Garlic**

Things that can activate lupus

- **Be wary of estrogen hormones**
 - **Pregnancy, BCP and HRT**
- **Stress – minimize**
- **Medications**
 - **Sulfa containing medications**
 - **Thiazides, NSAIDs**

Things that can activate lupus

■ Medications

- Stopping certain medication abruptly especially steroids (prednisone) – need a taper – gradual dropping of the dose

■ Avoid skin trauma

- Tattoos, skin piercing

SLE: Treatment Overview

- **Treatment will vary depending on the organ systems involved in your disease**
- **Example therapies**
 - **Prednisone – effective but many side effects**
 - **Hydroxychloroquine (Plaquenil®) – treats skin, prevents flares and cumulative organ damage**
 - **NSAIDs – useful for pain – caution: GI, BP, kidney**
 - **Aspirin – protects the heart**

SLE: Treatment Overview

▪ Non-medicinal therapies:

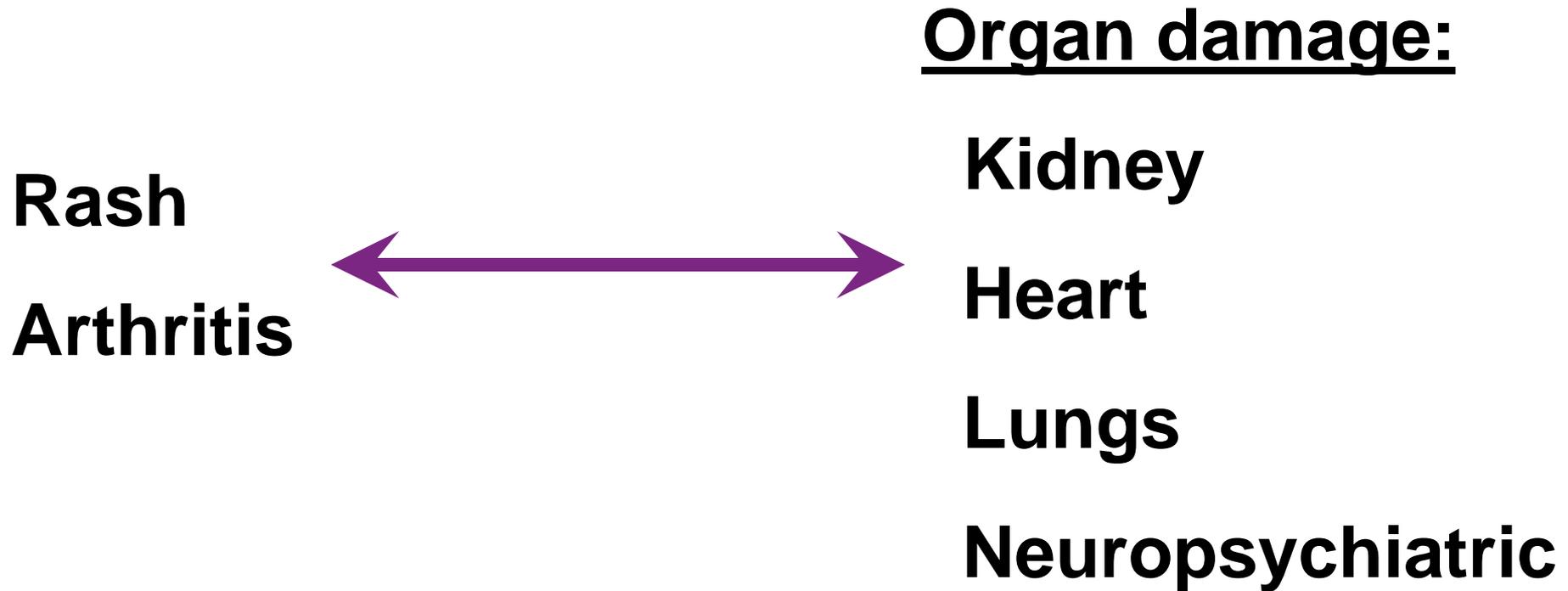
- Rest
- Limited sun exposure (between 10am – 4pm, most UV-B)
- Appropriate physical activity i.e. exercise
- Smoking cessation can improve antimalarial efficacy

Lupus Flare and Remission

- **A flare is a sudden increase in disease activity**
- **Remission is a duration of time that is free of disease activity**
- **Learn when to call your physician**

Prognosis for Lupus

Spectrum of disease



FACT:

Successful treatment of

LUPUS

— *often requires a* —

combination of ***medications.***



FACT:

With current methods of therapy,

80% to 90%

of people with non-organ threatening **LUPUS** can look forward to having the same lifespan *as people without lupus.*

Lifestyle Changes:

Living Better with Lupus

- **Exercise: *alternate with rest periods***
- **Ultraviolet light and florescent light: *take precautions to minimize exposure***
- **Diet and supplements: *there is no “lupus diet”, but healthy diet is recommended***
- **Smoking: *eliminate the habit***

FACT:

— People with **LUPUS** —

should eat a balanced diet that contains plenty of

Fruits and Vegetables,

Whole Grains,

and moderate amounts of

Fish and Lean Meats.

They also should quit smoking
as tobacco products can

trigger flares.



FACT:

People with **LUPUS** usually are *encouraged to engage in appropriate*



 **DAILY** 
EXERCISE

to maintain **muscle** and **bone** strength,
but they also need to balance exercise with rest.

FACT:

80%

of people
with **LUPUS**,

experience fatigue.

For some, **fatigue** can be debilitating

to the point of forcing

them to stop

WORKING.



Coping Measures:

Living Better with Lupus

- **Control fatigue: *learn to pace activities***
- **Control stress: *identify your stresses and use methods to control the stress***
- **Manage depression: *most episodes subside on own; inform your doctor if your depression is prolonged***
- **Manage anger: *don't let anger bottle up***



Coping Measures:

Living Better with Lupus

- **Resolve guilt: *modify thoughts and behavior***
- **Address workplace issues: *discuss needs with employer***
- **Address sexuality issues: *don't hide problems***
- **Develop good doctor/patient relationship: *find a physician who listens; be honest and responsive***

Lifestyle Changes:

Living Better with Lupus

- **Sleep: *prepare the mind and body***
- **Rest: *determine the amount you need***
- **Medication side effects: *communicate with your physician***

Community Agencies and Resources

- **Health, social service, mental health agencies**
- **Lupus Foundation of America – Georgia Chapter**

If you want to go fast, go alone. If you want to go far, go together.





THANK YOU!

