



Lupus and Social Security Disability

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The Lupus Foundation of America, Inc.

Vision

- A world without lupus. The organization will advance the science & medicine of lupus to find a cure and improve the quality of life for all people affected by lupus.

Mission

- The Lupus Foundation of America is the foremost national nonprofit voluntary health organization dedicated to finding the causes of and cure for lupus and providing support, services and hope to all people affected by lupus.

Lupus is the Prototypical Autoimmune Disease

Lupus is an unpredictable and potentially fatal autoimmune disease in which the immune system is out of balance, causing inflammation and tissue damage to any organ system in the body.

IMPACT^{OF} LUPUS IN THE U.S.

Estimated

1.5 MILLION
Americans Have Lupus

90%

OF PEOPLE WITH LUPUS
ARE WOMEN

15% OF INDIVIDUALS DIAGNOSED
WITH LUPUS ARE CHILDREN

15%

Source: *Lupus Foundation of America*

LFA's Strategic Focus

We Execute our Mission Through Three Core Strategies:

- 1) **Advancing the science and medicine of lupus**
- 2) **Increasing public & professional awareness** of the disease and advocating on behalf of all people with lupus
- 3) **Supporting people with lupus** and their professional health care providers

National Research Program

Bringing Down the Barriers

- **Directly funding researchers** at leading universities and medical centers to address gaps in understanding the causes, progression, and consequences of lupus
- **Leading special research initiatives** and forging collaborative efforts among stakeholders to address critical issues in the field of lupus
- **Advocating for expanded investment in research** from public and private sources

Directly Funding Researchers

LFA focuses on areas of lupus research where there is a gap in understanding or where the federal government, industry and other organizations have not sufficiently concentrated their efforts.

\$23 million to support more than 400 grants at nearly 100 centers

Adult stem cell transplantation
Biomarkers
Cardiovascular disease
Compliance and adherence
Diagnostic criteria
Environmental
Epidemiology

Male lupus
Mid-to-late stage translational
Nephritis
Neuropsychiatric lupus
Pediatric lupus
Pregnancy and reproduction
Quality of life
Skin

Leading Special Research Initiatives

- **Lewin Report**, *Overcoming the Barriers to Drug Development*
- **LFA-Flare**
- **Collective Data Analysis Initiative**
- **Physician Online INstrument Training (POINT)**
- **Mouse Model Meeting**
- **Biomarker Meeting**
- **LFA Lupus Registry**

Federal Legislative Accomplishments

**Comprehensive National
Epidemiology Study at the
Centers for Disease Control and
Prevention (CDC)**

- Total funding to date - \$16.62 million

**DHHS Office on Women's Health
(OWH)**

- \$2.4 million over 3 years to create first-ever national lupus awareness campaign—\$60 million in donated media to date

**DHHS Office of Minority Health
(OMH), Eliminating Health
Disparities in Lupus Initiative
(EHDLI)**

- \$2.6 million since 2009 for a Health provider education campaign—medical school curricula and physician education

SSA Lupus Disability Criteria

14.02 Systemic lupus erythematosus. As described in 14.00D1. With:

A. Involvement of two or more organs/body systems, with:

- 1. One of the organs/body systems involved to at least a moderate level of severity; and**
- 2. At least two of the constitutional symptoms or signs (severe fatigue, fever, malaise, or involuntary weight loss).**

OR

B. Repeated manifestations of SLE, with at least two of the constitutional symptoms or signs (severe fatigue, fever, malaise, or involuntary weight loss) and one of the following at the marked level:

- 1. Limitation of activities of daily living.**
- 2. Limitation in maintaining social functioning.**
- 3. Limitation in completing tasks in a timely manner due to deficiencies in concentration, persistence, or pace.**

The Impact of Lupus on the Body

Nervous System and Brain

seizures, psychosis, headaches, cognitive dysfunction, neuropathies, depression, low grade fever

Eyes & Mucous Membranes

ulcers in the eyes, nose, mouth or vagina, Sjögren's syndrome

Heart, Lungs

pericarditis, myocarditis, endocarditis, pleuritis, pneumonitis

Gastrointestinal System

nausea, vomiting, diarrhea, weight changes

Kidneys & Renal System

edema, hypertension, proteinuria, cell casts, renal failure

Musculoskeletal System

extreme fatigue, arthralgia, myalgia, arthritis, myositis

Reproductive System

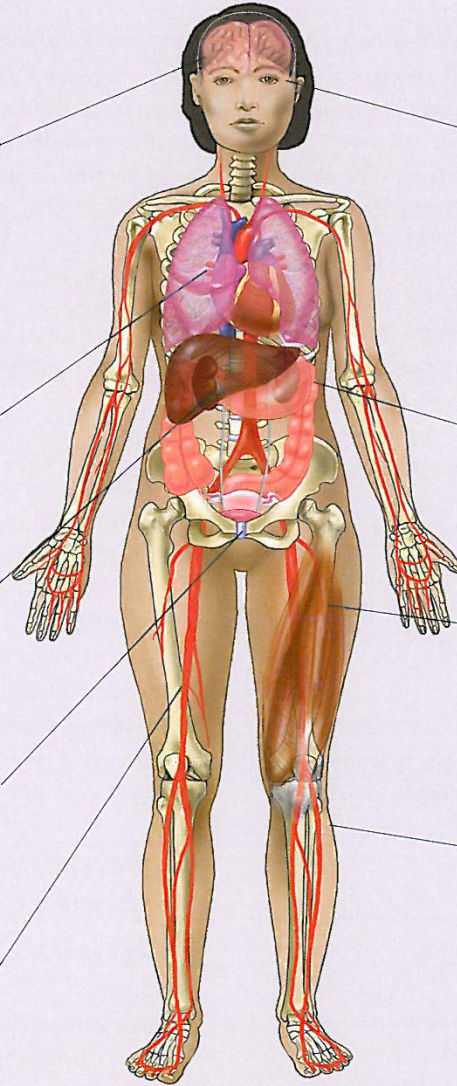
pregnancy complications, miscarriages, menstrual cycle irregularities

Skin

butterfly rash, cutaneous lesions, photosensitivity, alopecia, vasculitis, Raynaud's phenomenon

Blood

anemia, thrombocytopenia, leukopenia, thrombosis, autoantibodies, immune complexes



Brain and Nervous System (19 different subcategories)

- Cognitive dysfunction -- 80%
- Seizure Disorder
 - **Possibly affecting ability to get driver's license**
- Medications
 - **Causing mental impairments**
- Altered Consciousness
- Headaches
- Strokes
- Altered Behavior
 - **Psychosis**
- Movement Disorders

Heart and Lungs

- Pain in the chest on deep breathing (pleurisy) -- 40-60%
- Pulmonary embolism
- Pulmonary hypertension
- Interstitial lung disease
- Tachycardia
- Myocarditis
- Coronary artery disease
- Myocardial infarction

Muscles and Joints

- Mobility – Joint pain, joint swelling limited range of motion, difficulty of motion -- 95%
- Avascular necrosis
- Osteoporosis
- Oligoarthritis (2-5 joints)
- Polyarthritis (5+ joints)
- Rheumatoid arthritis
- Myositis --15%

Kidney Involvement -- 40%

Early Lupus Nephritis → Dialysis → Transplantation

WHO Class	Name	10-year (%) Dialysis Risk
III	Focal Proliferative	50
IV	Diffuse Proliferative	50-75
V	Membranous	30
VI	Glomerulosclerosis	High

Prolonged or Extreme Fatigue and Fevers -- 80% (flu-like symptoms)

- Active Inflammation
- Anemia
- Stress of Coping
- Medications

Recommendations to SSA

- Urge SSA to add lupus to the list of Compassionate Allowances
- Educate and train adjudicators about lupus
- Educate applicants that they do not have to reapply, but can appeal denial



Thank You!