

Living with Lupus: An Insider's Perspective

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My Own Story

“Is it Lupus Yet?”

■ *The What*

- What is “this”? Am I over-exaggerating my symptoms?
- What caused this?
- What do I do now?

■ *The When*

- When will the doctors understand?
- When will everyone else understand that I am not my former self?

■ *The How*

- How do I even manage to get up each day? Get down the steps? Drive to work? Take all of these meds?
- How am I going to perform my job? My duties at home?
- How do I get better?

■ *The Why*

- Why does it take so long to find out?
- Why can't I understand the long term goal?

My Own Story

“...But You Look So Good”

- Wearing the mask
 - Don't believe the hype. A picture doesn't always paint a thousand words
- Functioning with a disease that doesn't always have straight forward clinical signs and symptoms...
 - The great masquerader
 - Symptoms may precede blood test abnormalities
 - More than one medical issue may occur

Lupus

Definition

- A disease characterized by a malfunctioning immune system and inflammation
- Also called an autoimmune Disorder
 - The body “attacks itself”

Types

Discoid

- skin and hair only

Systemic Lupus Erythematosus (SLE)

- affects other organs

Lupus

Causes

- Generally not known
- Strong genetic component
 - Can “run in families”
- Environmental factors

People affected

- Roughly 1.5 million people in the US
- Highest rates in the Europe and Australia (more than in the US)
- Some races affected more than others
- Women > men

Lupus

Disease course

- Mild to severe
 - Depends on what organs affected
- Episodic or persistent
- May take months to years to diagnose
- Flares common
 - Episodes of worsening symptoms called “flares”
- Life expectancies have improved in recent years
 - Also depends on what parts of the body affected
 - Criteria to diagnose improved
 - Raised awareness
 - Medications

Lupus

Discoid Lupus

- Normally mild disease
- Skin and hair affected
 - Cosmetic issues
- Life expectancy typically not affected

Lupus

SLE

- Any organ affected
- Other symptoms and blood work abnormalities
- Most patients have fatigue and joint symptoms to some degree (>90%)
- Can mimic other diseases
- Life expectancy depends on the severity of disease and new treatments and earlier diagnosis have increased the overall survival

Central and Peripheral Nervous System

Seizures, Psychosis, Headaches, Cognitive Dysfunction, Neuropathies, Depression, Low Grade Fever

Heart, Lungs

Pericarditis, Myocarditis, Endocarditis, Pleuritis, Pneumonitis

Kidneys

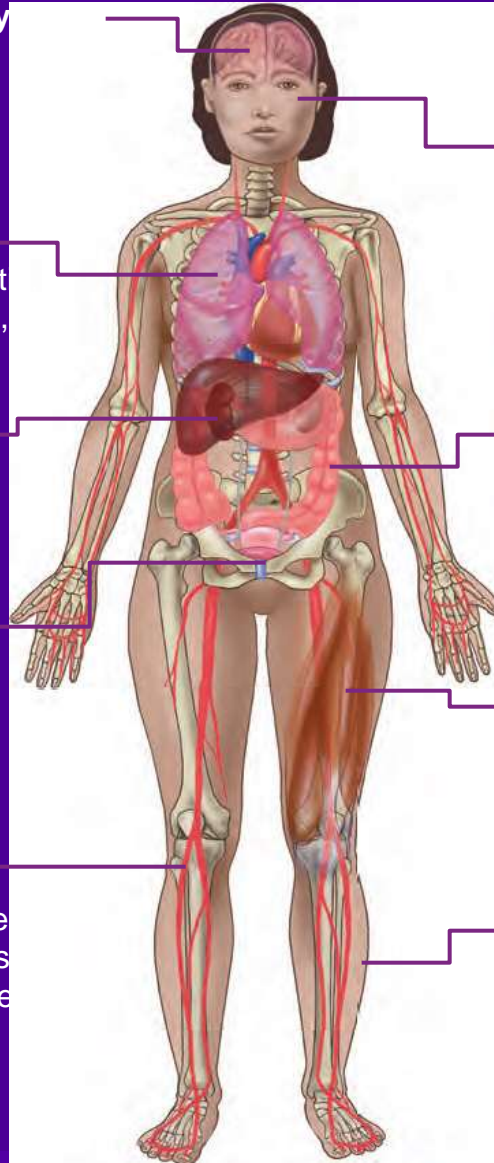
Edema, Hypertension, Proteinuria, Cell Casts, Renal Failure

Reproductive System

Pregnancy Complications, Miscarriages, Menstrual Cycle Irregularities

Blood

Anemia, Thrombocytopenia, Leukopenia, Thrombosis, Circulating Autoantibodies, Immune Complexes



Eyes and Mucous Membranes

Ulcers in the Eyes, Nose, Mouth or Vagina, Sjögren's Syndrome

Gastrointestinal

Nausea, Vomiting, Diarrhea, Weight Changes

Musculoskeletal

Extreme Fatigue, Arthralgia, Myalgia, Arthritis, Myositis

Skin

Butterfly Rash, Cutaneous Lesions, Photosensitivity, Alopecia, Vasculitis, Raynaud's Phenomenon

Diagnosis

- Based on criteria established by American College of Rheumatology (ACR)
- At least 4 categories including signs/symptoms and abnormal blood tests (ANA, dsDNA, anti-Smith antibody, abnormal blood counts, clotting antibodies, etc).
 - Should include one clinical and one immunologic criterion
- Symptoms may occur all at once or over a period of time. Thus, the timing of onset to diagnosis varies significantly for each patient

Lupus Treatments

No real cures

- Medications

- To suppress the immune system – to prevent the “attack”
- To treat the symptoms (joint pains, headaches, hair loss, etc.)
- Side effects

Lupus Treatments

Medications continued

Standard therapies

- Steroids, hydroxychloroquine/chloroquine/quinacrine, azathioprine, cyclophosphamide, cyclosporin, Rituxan®, aspirin

New things on the horizon!

- Benlysta® - first approved lupus drug in >50 years
- Other biologics in development
- Cellcept® (Roche)
- Improvements in transplantation (specifically for lupus kidney disease)

Lupus Treatments

Steroid side effects

- Weight gain
- Cushing facies (moon face)
- High BP
- High blood sugars
- Bone loss
- Muscle disorders
- Infections
- Mental affects
- Cataracts/glaucoma
- Hair loss or abnormal growth

Lupus Treatments

- Rest!
 - Improve sleep patterns
 - Simplify your life
 - Get family to help
- Reduce stress! (including meditation and prayer)
- Listen to the body
- Managing other medical issues (high blood pressure, high cholesterol, blood sugars)

The Path to Recovery


- Knowing symptoms
- Keeping a close relationship with your physicians
- Taking your medications as directed
- Understanding limitations at home and at work/school
- Accepting directional changes
 - If the same old thing isn't working, change it!
- Staying positive
 - Reflect on all of the battles you have already won
 - Making sure the inside catches up with the “look so good” - overall physical and emotional well being
- Controlling the disease instead of the disease controlling us

Questions?

More questions?




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The Cruel Mystery
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About the Lupus Foundation of America
We are devoted to solving the mystery of lupus, one of the world's cruelest, most unpredictable, and devastating diseases, while giving caring support to those who suffer from its brutal impact.

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