

# UNDERSTANDING LUPUS



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## AUTOIMMUNE DISEASES AND WOMEN'S HEALTH

### Autoimmune and Immune-mediated Inflammatory Diseases

The body's immune system keeps you healthy by recognizing any microscopic foreign material that enters your body, such as pollen, bacteria, or a virus. It then produces proteins called **antibodies** to target these foreign materials that could make you sick if they remain in the body. Once the resulting infection is controlled, this immune response stops and your health should begin to restore.

Sometimes your immune system mistakenly cannot tell the difference between the foreign material and your own cells. It malfunctions or wrongly attacks the body's healthy cells and tissues, often resulting in an inappropriate or excessive immune response. This activity can lead to the development of an **immune-mediated inflammatory disease (IMID)** that can cause inflammation and internal damage to almost any part of the body – from your joints and skin to your lungs and kidneys. **Autoimmune diseases** are a subset of IMIDs for which the antibody responsible for the abnormal immune response has been identified.

 **15-20 million** Americans have an autoimmune disease<sup>1</sup>

### Disease Prevalence and Impacts on Women

Autoimmune diseases are much more common in women than men. They can be challenging to diagnose because their symptoms can seem unrelated and mimic other conditions. They can also be difficult to treat, especially if the cause of the disease is not fully understood.

 **4 out of 5** people diagnosed with an autoimmune disease are women<sup>2</sup>

Some common autoimmune conditions that are more prevalent in women include:

- ▶ Alopecia areata
- ▶ Lupus
- ▶ Multiple sclerosis
- ▶ Psoriasis
- ▶ Psoriatic arthritis
- ▶ Rheumatoid arthritis
- ▶ Sjogren's syndrome
- ▶ Thyroid diseases

Understanding your risk of developing an autoimmune disease or IMID, recognizing early symptoms, and communicating frequently with your health care providers can help them to diagnose a condition early and help you to receive the care you need to feel your best.

## WHAT IS LUPUS?

Lupus is a chronic autoimmune disease where the body attacks its own tissues, creating widespread inflammation and symptoms throughout the body. This inflammation often results in organ tissue damage – most commonly in the joints, skin, brain, heart, lungs, kidneys, and blood vessels.

 **90%** of Americans with lupus are women ages 15-44<sup>3</sup>

 **50%** of Americans report knowing someone personally who has lupus<sup>4</sup>

## Types of Lupus

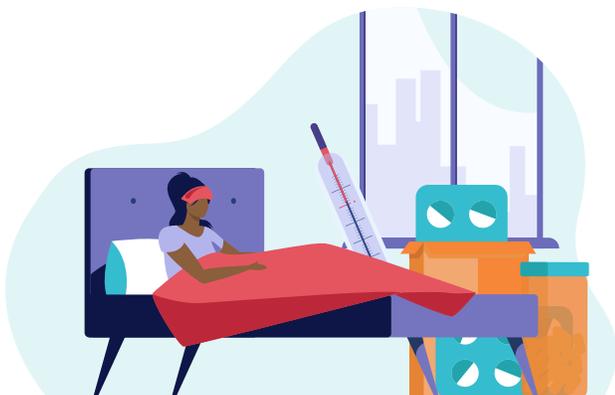
Lupus can take a number of forms, including:

- ▶ **Systemic lupus erythematosus (SLE)** – the most common type of lupus; symptoms can occur throughout the body, commonly affecting the kidneys, heart, hair, joints, and skin
- ▶ **Cutaneous lupus erythematosus (CLE)** – lupus that primarily affects the skin
- ▶ **Drug-induced lupus** – a temporary form of lupus due to reactions from certain medications
- ▶ **Neonatal lupus** – a rare form of lupus that can occur in infants of a mother with SLE

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**Some women may have incomplete systemic lupus erythematosus (iSLE); they experience some of the symptoms of lupus, without meeting the full criteria for SLE. Up to 55% of iSLE patients progress to established SLE.<sup>5</sup>**

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## Causes and Risk Factors

With many autoimmune diseases like lupus, it is not clear why the immune system mistakenly attacks healthy cells and tissues; however, it is likely that environmental and genetic factors play a role.

Risk factors for developing lupus:

- ▶ Sex and Age: women between the ages of 15 and 44 years old
- ▶ Race: African American, Asian American, Hispanic/Latino, Native American, or Pacific Islander
- ▶ Family history of lupus or autoimmune disease
- ▶ Existing diagnosis for another autoimmune disease or IMID

 African American and Hispanic women are **3-4 times more likely** to develop lupus than white women<sup>6</sup>

Women of color tend to develop lupus at a younger age, experience more serious complications, and have higher mortality rates. The LUMINA study found that African American lupus patients have more active disease with organ system involvement and lower levels of social support compared with their white counterparts.

## Common Symptoms

Symptoms of lupus are often a result of inflammation in the body. They may come and go, and they differ from person to person. The most common lupus symptoms include:

- ▶ Fatigue
- ▶ Pain or swelling in the joints
- ▶ A butterfly-shaped rash on the cheeks and nose
- ▶ Swelling in the hands and feet, or around the eyes
- ▶ Headaches
- ▶ Hair loss
- ▶ Sores in the mouth or nose
- ▶ Low-grade fevers
- ▶ Sensitivity to sunlight or fluorescent light
- ▶ Chest pain when breathing deeply
- ▶ Discoloration of fingers and toes when cold
- ▶ Brain fog



## LUPUS TRIGGERS AND FLARES

Even women with well-managed lupus experience periods of time when their symptoms become worse, known as symptom **flares**. Many women find there are a specific set of factors (triggers) - both in the body and the environment - that tend to cause their lupus to flare. Some examples of **triggers** include:

- ▶ **Estrogen** hormone levels
- ▶ High stress (emotionally or physically)
- ▶ Exhaustion
- ▶ Infection or injury
- ▶ Changes in lupus medications
- ▶ Exposure to the sun or ultraviolet light (photosensitivity)
- ▶ Certain medications (e.g., hormone therapy or medications that increase light sensitivity)

Every woman with lupus is different, and various triggers may not affect all people with lupus in the same way. Similarly, the symptoms that come with a lupus flare are unique to each individual.

Because flares can be unpredictable and spread out, it is common for women with lupus to go back and forth between extended times where symptoms are significant and times where disease activity is low. With an appropriate treatment regimen and symptom management, it is sometimes possible to have low enough disease activity that your lupus reaches **remission**.

Tracking potential triggers and flares can help you determine which triggers you need to avoid (if possible) and develop strategies to address them when they arise. Relevant tracking and health applications are in the **Resources for Women Living with Lupus** section of the SWHR Living Well with Lupus Toolkit.