

What You Need to Know About Lupus and Clinical Research

What is lupus?

Lupus is a chronic and complex autoimmune disease that can affect many body parts. It can impact the joints, skin, brain, lungs, kidneys, and blood vessels, causing inflammation and tissue damage.

There are five different forms of lupus:

- 1 **Systemic Lupus Erythematosus (SLE)** can affect many body parts, including the kidneys, heart, lungs, brain, blood, and skin.
- 2 **Cutaneous lupus** causes a rash or lesion on the skin, usually when exposed to sunlight.
- 3 **Drug-Induced lupus** is caused by an overreaction to certain types of medication.
- 4 **Neonatal lupus** occurs when an infant gets auto-antibodies from their mother with SLE.
- 5 **Incomplete lupus**

What are the signs and symptoms of lupus?

Some of the common signs and symptoms of lupus include:

- Fever
- Joint pain, stiffness, swelling (arthritis)
- Skin rashes, often on the face
- Low iron, low red blood count (anemia)
- Chest pain
- Hair loss
- Pale or purple fingers or toes
- Sensitivity to the sun (photosensitivity)
- A butterfly-shaped rash across the cheeks and nose
- Fatigue, feeling tired
- Mouth sores
- Headache, confusion, memory loss



FATIGUE



MALAR RASH



JOINT PAIN
& SWELLING



FEVER

You may have symptoms from lupus or from co-occurring conditions, also called comorbidities. Comorbidities may be related to the systemic inflammation caused by lupus.






How is lupus treated?

While lupus has no cure, treatments may control lupus symptoms and prevent organ damage.

Treatment depends on your signs and symptoms.

You should talk with your healthcare provider about the benefits and risks of different treatments. You and your provider may change treatments or adjust your dose if your disease flares or if you experience side effects.

MEDICATIONS USED TO TREAT LUPUS INCLUDE:

Medication type	Common uses
 NSAIDs (Nonsteroidal anti-inflammatory drugs)	Used to treat joint or chest pain, fever, and swelling, e.g., aspirin or ibuprofen
 Antimalarials	Used to treat lupus in general and help with fatigue, joint pain, skin rashes, and lung inflammation. Research shows that regular use of antimalarials may prevent lupus flares from recurring, e.g., hydroxychloroquine
 Corticosteroids	Used to treat lupus, dose depends on how severe lupus is. For patients with kidney inflammation, lung or heart involvement, and central nervous system symptoms, e.g., prednisone
 Immunosuppressants	Used to treat moderate to severe lupus, e.g., mycophenolate mofetil, azathioprine, cyclosporine and voclosporin, a calcineurin inhibitor
 Biologics	Targeted biologic agents used to suppress specific parts of the immune system which may be related to lupus, e.g., belimumab and anifrolumab

THE GOALS FOR TREATMENT INCLUDE:



Reducing the inflammation of tissues



Suppressing the immune system abnormalities responsible for tissue inflammation



Decrease lupus systems



Preventing lupus activity



Minimizing lupus complications

What is it like living with lupus?

Living with any chronic disease can be challenging and impact your physical and mental health. The same is true if you have lupus.

Lupus is difficult to live with because:

- It is **unpredictable**, with symptoms coming and going.
- It impacts **many different organs**.

Lupus may be unpredictable and is often invisible. People living with lupus may look well but not feel well.

Luckily, there are ways to manage lupus to help you feel better. Coping strategies can help you deal with stress

due to lupus. People use different coping strategies based on what works for them.

Some coping strategies include:

- Working as a team with your healthcare provider to treat your lupus
- Talking about lupus with your friends and family
- Practicing healthy lifestyle habits like exercising regularly, eating a balanced diet, and getting enough rest
- Learning stress management techniques like taking time to relax and slow down
- Finding a lupus support group

What is clinical research?

Clinical research looks at health and illness in people to add to our medical knowledge.

There are two common types of clinical studies.

1 OBSERVATIONAL STUDIES

- Researchers observe participants or evaluate data that was already collected to examine how characteristics or outcomes may change over time.
- No interventions are typically given or assigned in observational studies.
- These studies may help inform the use of a treatment or support a hypothesis to be further evaluated in a future clinical study.

2 INTERVENTIONAL STUDIES

- Researchers can test new ways to prevent, detect, or treat disease.
- Participants are typically in an intervention group (receives an intervention or treatment) or a control group (receives no intervention).
- Researchers compare outcomes from the groups to evaluate the effects of the intervention.

While these are two common types of clinical studies, other approaches are done as well. The type of clinical study used depends on the question researchers are trying to answer.

Why do we need lupus research?

We have learned a great deal about lupus, but there is still much more to learn, and we are still searching for new treatments and a cure. Lupus knowledge is advanced by the people who participate in clinical trials.

Medicines can affect people differently and must be tested among each potential patient group—by race, gender, age, and ethnic background so providers can know how to use the products safely and effectively. More diversity and representation in clinical trials will help find treatments that work for everyone.

Summary

- **There are many symptoms of lupus. Lupus can affect people in different ways physically and mentally.**
- **More research is needed to ensure the development of safe and effective therapies for the diverse lupus community.**
- **You can help advance lupus research.**

If you are interested in clinical trials, ask your provider(s) or contact **Lupus Therapeutics** (lupustherapeutics@lupusresearch.org), the clinical affiliate of the **Lupus Research Alliance**.