

LUPUS

What is it?

Lupus is a chronic systemic autoimmune disease causing the immune system to attack organs and tissues. Lupus is referred to as the “great imitator” because its symptoms mimic those of many other diseases. The inflammation caused by lupus can affect the joints, skin, kidneys, blood cells, brain, heart, and lungs. Lupus can affect anyone but there are certain people that are at risk including women ages 15-45 and those with a family member with a history of autoimmune disease. Racial and ethnic groups including Asian Americans, African Americans, Native Americans, Hispanic, and Pacific Islanders have also been identified at risk. Lupus can also affect children but as a variable disease it can present with or without the obvious signs and symptoms of Lupus. When children are diagnosed with Lupus they might have suffered from more organ damage than adults.

What are the common effects?

Lupus is known for alternating periods of flare up and remission. Symptoms can range from mild to life-threatening and can include:

- Extreme fatigue
- Headache
- Painful and/or swollen joints
- Fever
- Anemia
- Pain in chest
- Rash across cheeks and nose
- Photosensitivity
- Mouth ulcers
- Confusion and memory issues
- Shortness of breath
- Hair loss
- Reynard’s Syndrome (circulation)

What are the triggers?

Although every person is affected differently, common triggers for flare ups have been identified. According to the *Lupus Foundation of America* (2015), these triggers can include infection, cold or illness, injury, exhaustion, emotional stress, exposure to UV light from sun or bulbs, and medications including Sulfa drugs, Penicillin, and Minocycline.

What is the treatment?

A rheumatologist will usually lead the treatment plan and prescribe a combination of medicines aimed at controlling the symptoms of lupus. Goals of treatment include controlling an overactive immune system, managing symptoms like inflammation and pain, controlling flare ups, and minimizing potential organ damage. Commonly corticosteroids which can cause weight gain are prescribed.



Kennedy Krieger Institute

The **Specialized Health Needs Interagency Collaboration (SHNIC)** program is a collaborative partnership between the Kennedy Krieger Institute and the Maryland State Department of Education.

Suggested school accommodations

It is important to learn what information the student wants to share with peers and educators. Some parents believe it is beneficial for the student to learn to communicate about their condition and advocate for their accommodations. This is a personal decision for the student and family. Supporting students with this condition in the school require educators and parents/guardian to work as a team. Some accommodations to consider for a 504/IEP could include:

- PT/OT/SLP evaluation
- Modified or flexible school day
- Plan for absences and make-up work
- Preferential seating
- Flash pass for bathroom and health suite
- Breaks during the day, monitor for fatigue
- Classroom locations (try to decrease walking distance, need for elevator key)
- Extra time in hallways
- Safety restrictions for use of stairs, alone in hallways, etc.
- Adapted PE
- Limited sun exposure
- Copies of notes
- Computer access
- Extended time for tests (related to Lupus fog)
- No penalty to make up work missed due to appointments or absences
- Reduction of homework assignments
- Staff education/training as appropriate
- Emergency Evacuation Plan (EEP)

Specific health issues for Individualized Healthcare Plan

- Date of diagnosis with complete medical history
- Current medication list
- Pain or headache protocol including PRN medications
- Sun exposure protocol
- Physical accommodations and/or equipment
- Help educate student about disease including medication, side effects, advocacy in school
- Communicate with school staff, parents/guardian, and provider any changes or concerns about the disease
- Emergency Care Plan(s) (ECP) related to medical needs in the school setting and staff education/training as appropriate for each

Resources & Manuals

Lupus Foundation
Lupus.org

Lupus Research Alliance
<http://www.lupusny.org/>

Centers for Disease Control and Prevention: Lupus
<https://www.cdc.gov/lupus/index.htm>