

# LUPUS

## Background

Lupus is a 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 pain and inflammation caused by lupus can affect the joints, skin, kidneys, blood cells, brain, heart and lungs. Lupus can affect anyone but women ages 15-45, those with a family history of lupus or another autoimmune disease, and certain racial and ethnic groups are most at risk.

Lupus is known for alternating periods of flare-ups and remission. Signs and symptoms include:

- Extreme fatigue
- Painful or swollen joints
- Headache
- Light sensitivity
- Chest pain
- Butterfly rash across the cheeks and nose
- Skin lesions that worsen with sun exposure
- Hair loss
- Mouth sores
- Stretch marks related to changes in weight

Complications such as anemia, bone fractures, pneumonia, kidney failure, heart attack, seizure, and stroke are possible. Children may present with or without the characteristic signs and symptoms but may suffer greater organ damage compared to adults.

Common triggers for lupus flare ups include infection, illness, injury, and exposure to certain medications. Emotional stress and exhaustion can also contribute to flare ups. Environmental factors like exposure to certain lighting and changes in weather, temperature, and air quality can also cause or increase symptoms.

Nonsteroidal anti-inflammatory drugs (NSAIDs), corticosteroids, and immunosuppressants are most prescribed to help manage effects of lupus such as pain, inflammation and fever. Antimalarials work by reducing autoantibodies (proteins in the blood) that attack healthy cells and tissues.



## Top Takeaways for School Considerations

Lupus is a chronic autoimmune disease that can cause pain and swelling in nearly every part of the body. Symptoms vary from student to student, can change over time, and be life-threatening.

Brain fog is an extremely common symptom of lupus affecting a student’s concentration and memory.

Extreme fatigue is common. Students may benefit from scheduling adjustments (e.g., gradual return to school, adjusted school day, flexibility, blended learning).

Sensitivity to sunlight, fluorescent, or halogen lighting may require advanced school planning including sunscreen, long sleeve clothing, or screens on lighting.

Environmental triggers like temperature changes and air quality may also require advanced planning including temperature-controlled buses, fans, air filters or field trip accommodations.

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## Kennedy Krieger Institute’s Specialized Health Needs Interagency Collaboration

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



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## Considerations for the Individualized Healthcare Plan (IHP)

- Nursing diagnosis of fatigue, pain (acute/chronic), risk for infection and risk for impaired skin integrity
- Current diagnosed health condition including date of diagnosis, progress of disease process and other chronic health conditions
- Current medication and treatment orders (consider schedule, equipment needs and side effects)
- Use of specialized equipment, adaptive equipment, and orthotics
- Activity, positioning, transferring (consider precautions and/or restrictions)
- Consider emergency care plan(s) (ECP) and emergency evacuation plan(s) (EEP) as related to medical needs in the school setting, and staff education/training, as appropriate

## Discussion Starters for Educational Team

1. Has the school staff been trained to implement the student-specific emergency plan?
2. Would the student benefit from evaluations or assessments in any of the following areas: physical therapy, occupational therapy, speech and language therapy, assistive technology, adapted physical education, functional behavior, psychology, hearing and vision?
3. Would the student benefit from additional academic support and/or modified education (e.g., copies of notes, extra time, reduced workload, simplified instructions, alternative formats for presentation of material, 504/IEP)?
4. Can strategies be implemented to assist the student with executive function (e.g., plan, prompts, organizers, agendas)?
5. Would schedule flexibility support the student?
6. Is the physical school environment safely accessible for the student's mobility needs (e.g., entry and exit, ramps, location of classes, access to elevator, doorways)?
7. Can rest breaks, safe spaces or reduced stimulation times be built into the student's schedule?

## Resources

Lupus Foundation of America  
[lupus.org/](http://lupus.org/)

The Lupus Initiative  
[thelupusinitiative.org/healthcare-providers/schoolnurses/](http://thelupusinitiative.org/healthcare-providers/schoolnurses/)

Lupus Corner  
[lupuscorner.com/](http://lupuscorner.com/)



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[KennedyKrieger.org/HealthInformation](http://KennedyKrieger.org/HealthInformation) for more information.