What is Lupus?

Lupus is an autoimmune condition. Autoimmune means that the body’s own immune system (the thing that usually protects us from being sick) is working incorrectly. Normally, the immune system makes antibodies. Antibodies are the soldiers that help fight germs and infections. In lupus, the immune system cannot tell the difference between the good guys (the body’s own cells) and the bad guys. Since the immune system is confused it accidentally starts attacking itself. This causes inflammation. Signs of inflammation include redness, warmth, swelling, and pain.

The most common type of lupus is Systemic Lupus Erythematosus (SLE). This can affect many areas of the body including the skin, joints, kidneys, brain, muscles, heart, lungs. Lupus is known as the “disease of 1000 faces” because Lupus can look different in different people.
Class Rheum: Navigating School with Your Rheumatic Condition

By Jessica Guo and Ingrid Goh

Summer’s over and it’s back to school. For children with rheumatic conditions, going to school can be difficult and stressful. Children may be limited by their condition or the medications that they take. This can result in missed classes or decreased participation in activities due to symptoms or appointments. Completing school work may be difficult as well. Children may also feel worried about the social aspects of school as they may feel isolated or disconnected from their peers because of their differences. These obstacles can make school a scary place but there are different strategies and resources that can be used to make the process easier.

Before starting school, it is useful to communicate with teachers and administrators about your child’s condition. This will help them understand things that might affect performance, attendance, and other school-related aspects. That way they can adapt their lessons or help out if there is a problem.

Children need to have the courage and confidence to speak up. Self-advocacy is an essential part in making school-life safe and comfortable. This is why it is important that they know the name of their rheumatic condition and feel comfortable speaking about any symptoms.

It can also be very useful to develop a school wellness plan. This contains tools and resources that should be available in the classroom. A private space can be identified where children can rest and recover. When these are prepared beforehand situations can be taken care of quickly and safely.

In addition to interactions with teachers, friendships and relationships with peers are an essential part of a student’s sense of normalcy. Limitations may sometimes lead to social isolation—where it feels difficult to stay connected to peers.

There are different strategies that can help children maintain a healthy social life. If their condition is preventing them from going to school or attending events, try to stay connected through groups and online chats. It may also be helpful to do video chats or calls on days when it isn’t possible to go to school. Children can find ways to have fun with their peers and stay involved without straining themselves or being physically present.

There are many organizations that offer resources that can be used to make school easier for children and their caregivers. Online resources include letters and brochures that can be given to teachers to introduce the child’s condition. There are also educational videos that make it easier to communicate with teachers.

Here are some websites that you can visit for more information on:
General information about conditions  https://www.aboutkidshealth.ca/
Brochure that can be given to teachers  https://bit.ly/2qHe7hX

Want to Get Involved?

The Division of Rheumatology is seeking parents and patients to help in several areas. We are looking for:

- A member to sit on the SickKids Rheumatology Research Council
- Members to represent SickKids on the PR-COIN parent and patient working groups
  Please see https://pr-coin.org/families for more information
- Members for the SickKids Rheumatology Family Advisory Council and its subcommittees

Please contact us if you’re interested in joining:
  rheumatology.newsletter@sickkids.ca
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What Causes Lupus?
The specific cause of lupus is not known at this time. It is not a condition that is passed from one person to another through contact. There are some factors that may make someone more likely to get lupus: gender, race/ethnicity, family history, hormones, or a major stress or infection.

How Is It Diagnosed?
Since lupus affects many different parts of the body, getting information from the patient at the clinic visit is important, doing a physical examination and tests such as a blood test or urine test are usually necessary.

Some common signs of lupus are: rashes, painful & swollen joints, fever, muscle aches, loss of appetite, weight loss, sensitivity to the sun, or mouth sores, fatigue, chest pain and hair loss.

Is There A Cure?
There is currently no known cure for lupus, but the symptoms of the condition may be controlled with medications. Treatments are usually to manage inflammation and focus on making patients feel better.

Managing lupus involves preventing flares. Flares are times when the condition gets worse. During a flare-up, patients may feel more tired, sick, feverish and achy. Medications work to control the inflammation and reduce the risk of flares.

Screen Time: What is Recommended?
The Canadian Paediatric Society and Canadian Society of Exercise Physiology recommend:
- Screen time for children younger than 2 years is not recommended.
- For children 2 to 5 years, limit routine or regular screen time to less than 1 hour per day.
- Ensure that sedentary screen time is not a routine part of child care for children younger than 5 years.
- No more than 2 hours of recreational screen time for children 5-17 years.
- Maintain daily 'screen-free' times, especially for family meals and book-sharing.
- Avoid screens for at least 1 hour before bedtime, given the potential for melatonin-suppressing effects.

If your child is showing signs of being lonely, sad, overly tired, aggressive, or withdrawn, consider too much screen time as a potential cause of these signs. Contact your doctor to find out about other causes of these signs.

To learn more, visit:
https://www.aboutkidshealth.ca/Article?contentid=643&language=English
https://csepguidelines.ca/

Here are some examples of apps that may help decrease screen time:
Forest – Fully limits phone time; earn coins by planting virtual trees and use the coins to plant trees in real life.
OurPact – Can be used in a family or group to monitor everyone’s screen time.
Breakfree – Limits screen time or specific app time; sends warnings when time is reached.
Another Fun-Filled Summer At Camp Cambria

Photographs courtesy of Ingrid Goh

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