KLS FOUNDATION

KLEINE-LEVIN SYNDROME FOUNDATION

PATIENTS | FAMILIES | RESEARCH

WHAT IS KLS?

Kleine-Levin Syndrome (KLS) is a rare and complex neurological disorder characterized by recurring periods of excessive amounts of sleep, altered behavior, and a reduced understanding of the world. The disorder strikes adolescents primarily but can occur in younger children and adults. Kleine-Levin Syndrome (KLS) episodes are cyclical. Affected individuals may go for a period of weeks, months or even years without experiencing any symptoms, and then symptoms reappear with little warning. At the onset of an episode the patient becomes progressively drowsy and sleeps for most of the day and night (hypersomnolence), sometimes waking only to eat or go to the bathroom. Each episode lasts days, weeks or months during which time all normal daily activities stop. Individuals are generally not able to care for themselves or attend school and work. In between episodes, those with KLS appear to be in perfect health with no evidence of behavioral or physical dysfunction. KLS episodes may continue for 10 years or more. KLS is sometimes referred to in the media as "Sleeping Beauty" syndrome.

WHAT CAUSES KLS?

The cause of KLS is not known. An episode of KLS is sometime preceded by an infection, head injury, alcohol intake or sleep deprivation, however some episodes have no apparent triggering event. Researchers are looking into genetic, auto-immune, inflammatory or metabolic involvement. There is research going on at several laboratories around the globe, including Stanford University.

WHAT ARE THE SYMPTOMS OF KLS?

In addition to excessive sleep (hypersomnolence), a KLS patient's whole demeanor is changed. Some common KLS symptoms include:, cognitive impairment and derealization (dream-like feeling), confusion and memory loss, irritability or aggression, apathy or lethargy, regression (childlike behavior), repetitive behavior (taping, repeating questions or songs) difficulty with visual and auditory info, hypersensitivity to noise and light, reduced inhibitions resulting in food cravings (hyperphagia) and/or instances of hypersexuality. However, symptoms vary from patient to patient, and may change and evolve throughout the course of the illness. The absence of any of the above does not mean a patient does not have KLS.

HOW IS KLS DIAGNOSED?

There are no definitive tests for KLS. Diagnosis is based on a clinical interview with the patient and their family and exclusion of other conditions. As the person with KLS often has little or no memory of an episode, it is important for the parents or other care givers to be present at medical consultations. Parents will usually describe a teenager who is different from before.

WHO GETS KLS?

KLS is extremely rare, estimated at 1-2 cases per million people. KLS usually starts in adolescence but can occur in younger children and adults. KLS affects both males and females.

WHAT TREATMENTS ARE THERE FOR KLS?

There is no known cure or effective treatment for KLS at this time. KLS episodes may continue for 10 years or more but episodes of KLS stop occurring in many patients by the time they are 30 years old.

For additional information on KLS and how to get involved visit: www.klsfoundation.org