KLS Medical Advisory Board

The KLS Foundation Medical Advisory Board provides guidance to the Board of Directors on medical issues. This Board is composed of experts in disciplines relating to KLS, including neurology, sleep disorders, endocrinology and clinical research.

Medical Advisory Board

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Donate to the KLS Foundation

Your contributions assist in maintaining the ongoing success of the KLS Foundation's efforts to educate, support and find a cure for KLS. All funds support KLS Foundation projects.

Our main goals are to:

- Provide information and support to patients and families
- Increase physician awareness
- Promote and fund medical research

The Kleine-Levin Syndrome Foundation, Inc. is a 501(3)c non-profit organization.

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Kleine-Levin Syndrome Foundation, Inc.

What is Kleine-Levin Syndrome?

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. 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 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.

In addition to excessive sleep, a Kleine-Levin Syndrome (KLS) patient's whole demeanor is changed, often appearing "spacey" or childlike. When awake the patient experiences confusion, disorientation, complete lack of energy (lethargy), and lack of emotions (apathy). Most patients report that everything seems out of focus, and that they are hypersensitive to noise and light. In some cases, food cravings (compulsive hyperphagia) are exhibited. Instances of uninhibited hyper-sexuality during an episode have also been reported.

Kleine-Levin Syndrome (KLS) episodes are cyclical. When present, KLS symptoms persist for days, weeks or even months, during which time all normal daily activities stop. Individuals are not able to attend school, work or care for themselves. Most are bedridden, tired and uncommunicative even when awake. Not everyone affected by KLS exhibits all of the symptoms described above.

Affected individuals may go for a period of weeks, months or even years without experiencing any symptoms, and then symptoms reappear with little warning. In between episodes, those diagnosed with KLS appear to be in perfect health with no evidence of behavioral or physical dysfunction. However they function daily with the frightful reality that they could become sick again at any moment. KLS episodes may continue to reoccur for a decade or longer with devastating effects on the adolescent's life and family. KLS robs children and young adults of big pieces of their lives, one agonizing episode at a time.

The mean diagnostic delay for proper Kleine-Levin Syndrome (KLS) diagnosis is four years. This means that it takes the average KLS patient four years before receiving an accurate diagnosis causing undue suffering to patients and families. The cause of Kleine-Levin Syndrome is not known.

The KLS Foundation provides information and support to those diagnosed with KLS and their families. The Foundation exchanges information with patients and the medical community to help in the diagnosis and care of those affected by KLS, and supports research programs. Our goals are to raise awareness, support scientific research, to find effective treatment and ultimately a cure for Kleine-Levin Syndrome.

KLS Research

The KLS Foundation supports research to investigate the cause, treatment and ultimately a cure for KLS. By providing initial seed funding, research has now blossomed into programs at leading academic and hospital centers around the world, including Stanford University (California), University of California (San Francisco), Tel Aviv Medical Center (Israel), Hôpital Pitié-Salpêtrière (Paris) and University of Linkoping (Sweden). These efforts led to Prof. Emmanuel Mignot of Stanford University receiving the first NIH grant for KLS research, a very competitive five year research award. Dr. Arnulf and colleagues at Stanford have published a key review paper ("KLS: a systemic review of 186 cases in the literature," Brain, 2005) and the results of a large study in which KLS clinical data and blood samples were analyzed ("Kleine-Levin Syndrome: a Systematic Study of 108 Patients," Annals of Neurology, 2008).