IN THE CLOSE OF THE EYELIDS

You enter the fairy tale when

you experience ...

Excessive Sleepiness

Binge Eating

Hypersexual Behavior

Lethargy

Apathy

Confusion

Irritability

Delusions

Hallucinations

"The KLS Foundation was founded in 1999 by the Maier family. They hope this non-profit organization will help patients and families cope with the episodes, provide the medical community with information to find a cure, and raise awareness to this very rare sleep disorder."

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If you or someone you know display KLS symptoms, please contact Stanford's Center for Narcolepsy. Every patient studied will bring further progress to KLS research.

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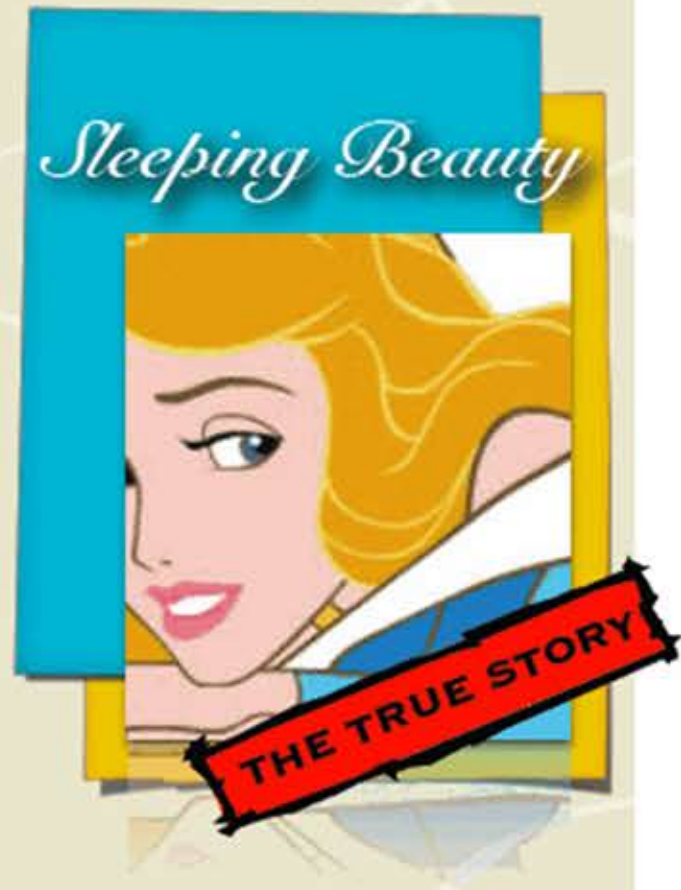

THE REALITY BEHIND THE KLEINE-LEVIN SYNDROME

"When lives are put on hold..."

HISTORY

Popularly known as the Sleeping Beauty Syndrome is the sleeping disorder marked by excessive sleepiness (up to 20 hours per day) for a couple of days or weeks at a time. It was described by German psychiatrist Willi Kleine, who noted these unusual symptoms in a Frankfurt clinic in 1925. Kleine went on to illustrate nine cases of this hypersomnia. Then in 1929 and 1936, New York psychiatrist Max Levin contributed to Kleine's research and gave evidence of a connection between the cyclical somnolence and excessive food intake (hyperphagia). Adding 11 more cases to this disorder, British neurologist MacDonald Critchley officially named it the Kleine-Levin Syndrome (KLS), which is also referred to as the Kleine-Levin Hibernation Syndrome, Familial Hibernation Syndrome, Periodic Somnolence and Morbid Hunger, and Kleine-Levin-Critchley Syndrome.

The Kleine-Levin Syndrome (KLS) is a rare neurological disorder that affects only about 500 people in the world. The medical community has been unable to pinpoint the exact cause of KLS, but some physicians have shed some more light on this unique disorder. In 2005, the American Academy of Sleep Medicine released information about a connection between KLS and a malfunctioning hypothalamus, the place in the brain that controls the drives of sleep, food, and sex. Dr. Emmanuel Mignot, the Director of the Center for Narcolepsy at Stanford, elaborated on these findings in 2006 when he agreed that it was very likely that the thalamus and hypothalamus were affected when KLS occurred. He also suggested that there may be a genetic vulnerability in KLS patients.

KLEINE-LEVIN SYNDROME

KLS patients have Educational Rights and Disability Rights. The medical community is currently trying to find a cure to this very rare sleep disorder in hopes that adolescents diagnosed with KLS will no longer miss out on special parts of their lives.

PEOPLE MOST AFFECTED

- Typically hits at puberty, abates gradually by mid-twenties, and mostly vanishes by about thirty
- Males affected four times as more than women
- Takes women 10-12 years to heal while it takes men 6-8 years
- Seems to affect Jewish people more than it does others; Israel has the most KLS cases than any other country in the world

TREATMENT

- As of right now, there is no cure.
- Treatment consists of combination of behavioral therapy and stimulant drugs.
- Pharmacotherapy / Stimulants: amphetamines, methylphenidate, modafinil, lithium, carbamazepine, and valproic acid.

K L S

- Not all patients experience all of the symptoms described.
- Some mood or other sleeping disorders display similar or sometimes even the same symptom.
- Clinician has to carefully differentiate in order to diagnose

WHOAH! ACTUALLY!

- May recur in adulthood (but unlikely)
- No association with mortality reported

WOW! REALLY!

- Mean diagnostic delay for proper diagnoses is four years

K L S

SYMPTOMS

People with KLS commonly display symptoms of hypersomnolence, hyperphagia, and hypersexuality. During an episode, patients sleep up to 20 hours per day (typically for 10 days but can last longer). They only wake up to eat or go to the bathroom. The mean frequency of episodes may be 2 per year, but it can vary from 1-12 episodes. Between episodes, they appear normal and healthy, except for the fact that a constant fear of unexpectedly falling into another episode lingers within them. Prior to a KLS episode, patients may have flu-like symptoms and on the onset of an episode, they are unable to do work or care for themselves. Patients perceive things out of focus and are hypersensitive to many sensory stimuli. Their whole demeanor changes and they come off as "spacey" or childlike. They also experience disorientation, lethargy, and apathy. Other behavioral disturbances linked to KLS include vivid imagery, motor retardation, pathological guilt, hallucinations, and suicidal tendencies.