**A long story about our daughter.

Rare disease day is February 29th. Here is a story of our daughter who is a very special, rare disease story.
Our daughter was a happy 13 year old who enjoyed school and who was loving life. For most of her life, she had recurring strep infections that were responsive to antibiotics within about 36 hours. Even after a tonsillectomy she would get these strep infections. But in the eighth grade, her recovery times extended to about 2 weeks. We noticed that she was sleeping 16 - 20 hours a day. She would be non - communicative, light and sound sensitive, and just slept all the time. And then the frustration began with seeking medical help for our daughter.
The trip from doctor to doctor proved pointless. No one could provide answers as to why she would get strep, or flu, or whatever else they called it on that visit and why she wouldn’t get better. Influenza A would then test positive for Influenza type B. But nothing helped. She just looked flu like and slept. Mono? Positive for Epstein Barr but they said it wasn’t mono. Pulmonologist couldn’t help the dry hacky cough. An endocrinologist found no abnormalities. No answers, no help, no direction. And we won’t even go into the situation with her education. Some teachers were helpful; others were doubtful – even rude.
An immunologist concluded that this was stress induced illness. So family counseling was sought. They too did not know what it was, but it definitely was not stress induced nor were there signs of depression. She continued to be well for about 2 weeks, get strep, and go to bed for two weeks. It was like a light switch – sick, then just as suddenly, wellness and our daughter was back!
A friend saw a story and told us about Klein Levin Syndrome (KLS). We researched this and found that many of the symptoms were exactly like our daughter!
A sleep doctor was consulted who said he didn’t believe it was KLS because her “episodes” came too often. Another opinion was sought and answers began to come to light. This doctor wasn’t positive but approached the case with a scientific model and set out to prove that this was not KLS. After his studies, and those of a psychologist, they concluded that this was not a mental issue. They concluded she was a KLS patient.
An empty world was now encountered. We had the diagnosis. Our search for doctors could stop. But, there weren’t definitive treatment options for KLS. We do work with a physician who has taken interest in helping find solutions.
The average diagnosis time for KLS patients has gotten shorter; yet, this is still typically a few years on the doctor trail seeking help. Many patients are misdiagnosed with depression and or bipolar disorder. They lose friends and connections due to their illness. The teen years are critical for social development. These kids sleep through a large portion of those years. Today, our daughter is 17 and slept nearly half of 2011. Her car just sits there. Her phone quit ringing. There is no texting. Just a girl sleeping.**