



This is a translation from Flemish to English of an article on the above web site – the link is here - <http://radiorg.be/node/605> - thanks to Sylvie and Chiara spreading the word in Belguim!

Testimony KLS Chiara

My daughter was just 14, just started in the 3rd secondary, in a new school, a new direction. In mid-September she was suddenly very difficult to wake up. She slept 22 to 23 hours a day, we shook her awake to eat and / or drink, she craved huge amounts of food, but then went right back to sleep. We thought initially it was a harmless flu.

After my daughter was still asleep after 3 days, we called the family doctor. He suspected meningitis, he sent us to ER. At the ER Chiara was very confused, she had no idea where she was, and she was very anxious.

My daughter was immediately admitted at pediatrics, where very many tests were done: blood tests, spinal tap, MRI of the brains, scans, EEGs, heart studies, epilepsy testing ... Everything was normal. Besides the EEG showed "slow lines". My daughter showed very abnormal behavior, still slept a lot, was very anxious, and even was wandering the hospital parking lot in pajamas and bare feet when we tried to get away!

The doctors did not know more ... all tests were negative ... it had to be "something psychic" ...

The hospital psychologist was called. Chiara said nothing and did not want to stay in the room with her, my daughter was extremely anxious and I saw that she did not understand what the psychologist asked her ...

After 4 days we were released from the hospital, with, in our pocket, the number of a psychological center.

We did not understand this. I do know my child. When she is "healthy", she is a clown, very communicative, open and positive, she has many friends, school went well, ...

After a few days in sleep mode, Chiara had a very severe headache, the doctor suspected that this was due to the lumbar puncture. That day after, Chiara was back "normal". Both for her and for us this was a very confusing time. We talked to her; she assured us that nothing had happened that could explain this "episode (11 days)".

About 6 months later, Chiara had her 2nd episode. This one lasted for 22 days. Now we are really worried. In this period, we see a report on TV about a teenager with Kleine-Levin syndrome (KLS), Alanna Wong (USA). Our eyes and our mouth drops open. This is so recognizable! We begin to search for information on the Internet, there is little known about this extremely rare neurological disorder. On the KLS Support Group from the USA, we find a Belgian (French speaking) neurologist who knows this syndrome, and he wanted to see us in Uccle.

After a 1.5 hours, the professor confirmed our suspicion and wanted to do a sleep study. This can only be done during an episode.

After 5 months. Chiara went back into episode. We contacted the neurologist in Uccle and went for a 12-hour sleep study. Chiara panicked completely, the room was equipped with cameras. Chiara gets all electrodes pasted on by a nurse. Chiara was convinced that the nurse is a troll. She was now hallucinating and she was very restless.

The results of the sleep study: Very technical, but it boils down to this: not conclusive for KLS, but abnormal sleep

patterns. We obtain the following solution: Ritalin (to keep her awake). If this is not working: Provagil (medicine for narcolepsy), if this does not work: Lithium (mood stabilizer, is mainly given in bipolar disorders).

We try the Ritalin, but Chiara is even more anxious, probably because she cannot escape from the hallucinations during sleep. We stop the Ritalin after 3 days. We think Provagil is not the right medicine either.

In another episode (8 months later), I put Chiara in the car, and drive it to the ER at UZG, and I DEMAND that we be seen by the head psychiatrist pediatrics.

This doctor is yawning during the consultation, is listening with very little respect and he decides that there is nothing wrong with my daughter. I'm really desperate. During these episodes, I lost my daughter, she is experiencing these episodes as if she is stuck in a nightmare, and I cannot help her.

Through friends we hear of a very highly acclaimed neuro-psychiatrist, and soon we have an appointment. Chiara's EEGs was taken again (outside episode), every 3 weeks Chiara went for consultation, but during episode she did not say a word. This doctor had seen Chiara during two episodes, and about 1.5 years outside episodes.

His conclusion was that Chiara her brains "blocked" when prolonged excess stress or lack of sleep. This doctor prescribed a medicine based on herbs and arrangements with a psychologist. During a next episode, the professor suggested that we should be stricter with Chiara and should force her to go to school.

I am very angry. During an episode this child not knows where she is at that moment, she is not awake, she see and hear things that are not there, and she cannot communicate! Our suspicion of KLS was laughing off the table by this professor a few months ago.

We stop the consultations with this doctor and the psychologist immediately.

Meanwhile Chiara, in between episodes, a very normal, fun teen! The fear of another episode now dominated our lives.

I am still insistant something is wrong, I am also sure that "this problem" is not "psychic" and I contact the department of neurology at UZG. A few months later we finally have an appointment.

A young neurologist allows us to speak. I am very skeptical, and really want to see the department chief. But this doctor immediately sets the right questions, He recognizes we suspect (KLS) and is prepared to provide the necessary investigations. I give him all the medical records of the recent years.

Several studies (EEG,'s scan, blood tests, DNA testing, 24 hour monitoring, sleep study's -in AND out episode-) and 1 year later our suspect is finally confirmed! Chiara is indeed suffering from Kleine-Levin syndrome.

It has taken us 4 years before we got the right diagnosis. KLS affects 1/1.000.000 (mainly) adolescents. There is no medicine that cures this disease (yet).

It remains difficult to organize; we never know when an episode will begin, and how long they will last. The eighth episode lasted 118 days. Our family life falls completely silent then and everything is a function of Chiara. We know now what condition my daughter suffers from and so we can properly care for her. Chiara is now almost 18. After each episode we hope it is the last.