

**Waking up to reality**

By Claire Droney

Wednesday, May 09, 2012 – Irish Examiner

Claire O’Neill can sleep for 10 days at a time. Could a flu jab be the culprit, asks Claire Droney

CLAIRE O’NEILL, 17, will be on a camper-van holiday with her parents this weekend, driving from their home in Bray down the east coast. Her dad mock-groans at the thought of clothes shopping with her, but he is delighted. Time with his daughter is precious. Claire can become disorientated, falling asleep for up to ten days.

Claire is a member of sufferers of unique narcolepsy disorder (SOUND), a group established by parents who say their children developed narcolepsy as a result of the Pandemrix swine-flu vaccine. Recently, the Department of Health confirmed a link between Pandemrix and narcolepsy in children aged 5-18 years.

But Claire doesn’t have narcolepsy. She has Kleine Levin syndrome (KLS), or sleeping beauty or Rip Van Winkle syndrome. KLS is a rare neurological disorder, affecting one and two people per million. Often brought on by an infection or the flu, it can cause sufferers, usually adolescent males, to fall asleep for days.

Other symptoms include hallucinations, hypersexuality, which occurs mainly in males, and depression, which occurs mainly in females. Between episodes of sleeping, people with KLS feel normal and it is common to grow out of the syndrome after the ages of 8-14 years. People with narcolepsy feel sleepy everyday, and never revert to pre-narcolepsy.

Claire’s parents say she contracted KLS from Pandemrix two years ago. "We’re convinced of it. Prior to Claire getting the vaccine, we had a very healthy girl. We gave Claire permission to get the swine-flu jab because we were told it’s the safest thing for our child," says Claire’s mother, Christine O’Neill.

"So far, no-one has said that there is or there isn’t a link between the swine flu jab and KLS, but the HSE contacted us this week to say they want to organise a psychologist for her and are going to speak with the Department of Education to get her extra help for school."

Since the onset of KLS two years ago, Claire has had numerous sleepy episodes, the longest for 10 days. During these episodes, her parents wake her up to feed her, bathe her and help her to use the toilet. She has ‘weird episodes’ where she feels she is sleepwalking while awake — she cannot function and becomes hypersensitive to noise and light. She can also have frightening hallucinations.

"Claire has missed out on a year and a half of her normal teenage years," says Mrs O’Neill, who is Claire’s carer during episodes. Last year, the family went to Lanzarotte for a week and Claire slept. She books tickets for discos and the cinema and cancels due to sleep or disorientation. She misses 14 days of school per month. She was awake for her Junior Certificate but is afraid she will be asleep for her Leaving Certificate.

When Claire wakes up after days, she is ravenous, craving cheese burgers and chocolate. "It’s very hard for me to tell someone that my daughter can sleep for ten days and that I have to shower and feed her like a two-year-old. Sometimes, she speaks to you like she’s a five-year-old and other times she’s just tired and disorientated.

"She looks exhausted after a sleepy episode, with huge dark circles under her eyes. She’d ask me, ‘did I dream it or was it real? Was that person real’? It’s not fair on Claire, I feel sorry for my child — she should be in school, and out with her friends," says Mrs O’Neill.

Before being diagnosed, Claire underwent tests including lumbar punctures, MRI and CT scans. Then she was sent to a child psychologist for 18 months. "I knew it wasn’t stress or depression. I just knew there was something else wrong with my child. This is a girl who is normally quiet, causes no trouble, and all of a sudden she can go to sleep and start hallucinating," says Mrs O’Neill.

"We thought it was in her head," says Claire’s father David. Last summer, the O’Neills read a newspaper article about a KLS sufferer.

They brought Claire to the Mater private sleep disorders clinic in Dublin, and within an hour the specialist had diagnosed Claire.

"In a way, I was glad to get a diagnosis, because it meant at least I’m not the only person with it," says Claire. Dr Catherine Crowe, who diagnosed Claire, has only encountered three cases of KLS in 25 years, two in Ireland and one in France.

"KLS is extremely rare and we don’t really know the incidence of it. It would be easy to mix KLS up with depression as it can be associated with the mood going up and down ... I can’t say it was related to the vaccine and I can’t say that it wasn’t," says Dr Crowe.

Lithium is prescribed for KLS, but it did not suit Claire. "When Claire’s good, she’s like a normal 17-year-old. But you could have three days when she’s fine, and nine days when she’s asleep, and three days fine again. You’re constantly on tenterhooks and you can’t plan anything," says Mrs O’Neill.

"It gets harder as she gets older. Claire will have to pick a college near to home. Her choices are very limited because of her condition. Who’s going to give Claire a job in the long-term? Will she be able to hold down a relationship or a job? I’m just hoping that Claire will grow out of it," Mr O’Neill says.

Claire hopes to become a garda or work in airport customs, but is worried about being asleep during her Leaving Certificate exams next year.

"I genuinely do not want to repeat sixth year, but if I’m asleep during the Leaving Cert, I’ll have to repeat it next year. They said they’d send someone to the house to help me, but I can’t even talk or write during an episode," says Claire.

"It makes me think if I hadn’t got the jab, would I still have KLS now?"

Claire is pragmatic about her condition, refusing to succumb to a ‘why me’ attitude. "One of my teachers greets me after I come back after an episode by saying ‘Did you have a nice sleep?’ And I like that," says Claire, who is also grateful to her boyfriend Patrick for understanding and accepting her condition.

The family choose small positive goals to focus on for Claire, the next being to attend the final Westlife concert in Dublin in June.

"I’m not a bit embarrassed about going to Westlife with my mother," she says.

"I’ve always loved them and I hope I’m awake for the concert."