



Mikaylas Story

By Tricia Brockel Renier – August 2013

Mikayla was in 5th grade when I first started having problems with getting her up for school. Like most parents, I thought she was just being a typical kid and being difficult. She, typically, slept 12 hours every night so I just could not understand why she would still be tired. It led to a lot of frustration on both our parts and many a fight to get her off to school.

This continued all through Junior High. Her absences were ridiculous, but she seemed to catch every single illness that went around so I didn't know what else to do but let her stay home and recuperate. The doctors certainly didn't have anything to say other than she had caught another bug.

The Summer before Mikaylas Freshman year of high school she was watching the History Channel on something they were referring to Sleeping Beauty Disease (We prefer Kleine Levin Syndrome as the media tends to romanticize the disorder when there is nothing romantic about it.). She seemed to identify with it very much and asked me, Mom? Could that be what is going on with me? I was drying dishes and hadn't paid much attention, but I immediately dismissed the idea and told her No, it is too rare.

A couple days passed and something kept nagging at me about that conversation. I wondered why my daughter related so much to that news story. I decided to begin researching it. The more I did, the more I saw exactly why Mikayla saw herself in that story. I wasn't ready to take it to our paediatrician yet though.

I decided to do 6 months of logging her life. In the Fall of her Freshman year, I took it to her doctor and showed her the log and mentioned Kleine Levin Syndrome. She had heard of it, but knew nothing about it and immediately sent us to Billings to a Pediatric Neurologist. He did some testing, talked to us at length, and sent us home. Here she did a sleep study with a MSLT. A MSLT is a test they do to identify Narcolepsy. As it turns out, Mikayla hits REM sleep in 58 seconds to 2 minutes. It takes the average person 90 minutes to achieve REM sleep, which is the most restful, deep sleep a person can have. One problem though, Narcolepsy did not explain her long periods of sleep and behaviors she displayed when sleeping

anywhere from 15 hours per day to 22 hours per day. After much discussion, it was decided that she had both Narcolepsy and Kleine Levin Syndrome. Mikayla takes Nuvigil to control her Narcolepsy, however; there is absolutely no cure for Kleine Levin Syndrome. They do not know what causes it. There is no cure for it. There are no medications to control it. As strangely as it appears in a child's life, it typically will disappear sometime in their 20s. This is not always the case as I have heard of others in their 40s still struggling with it. Mikayla's longest KLS episode has lasted 67 days straight where she slept approximately 22 hours each day.

Mikayla has missed 60% of her Freshman year and 60% of her Sophomore year. She has a tutor who helps her and has spent this Summer working on school work to catch up to her peers. She will be starting her Junior year as a Junior! I am so proud of her. (Go Mikayla!) All the obstacles that life has put in her way well, that is quite an accomplishment and shows her dedication and determination not to let these health issues get in her way.

Her Sophomore year did end with more health issues. She missed the last 5 weeks of school because she kept passing out unconscious. Great Falls doctors had no other resources to find out what was causing these unconscious drops and she had to be Mercy flighted out to Spokane.

We now know that she also has a developed a disorder in the family of POTS syndrome. Thankfully, this one is controllable! Mikayla came home with a wheelchair, walker, and crutches. She has spent the Summer relearning to walk and continues with physical therapy. All the falls she took over the course of two months left her unable to move her legs after the final fall. She did regain use of her left leg, but her right leg was injured so much with the repeated falls that it left her unable to use it. Mikayla is strong willed and she has come back with flying colors. She is walking, putting all the assistance devices behind her, but continues to be in a lot of pain with that leg. It is lessening and her physical therapists say that a few more weeks and she will be done with therapy. Yea!

All in all, we as a family are doing the best we can to help her. Many times it is just a matter of keeping her spirits up. It is hard when you are a teenager and your friends carry on without you because you are sleeping life away. Friendships end because people do not understand where and why you've been out of school for so long no matter how many times you try to explain it. Holidays are slept through. Mikayla has missed Thanksgiving.

One Easter she was functioning awake but after coming out of episode-she had no recollection of many of the events or who all was present that day. Functioning awake means that Mikayla can appear to be normal and going through her day, but after coming out of a KLS episode she will remember nothing or only parts of the day/days. Mikayla has lost as much as an entire week of school and daily life while functioning awake.

As her Mom, I worry all the time. Every morning I wonder when I go to wake her what will be in store for us. Doctors just are not aware of this disorder and do not understand it. Many attempt to treat it, but inappropriately. They try their best. So little is known about it. I found a support group online through a dear girl who also suffers from Kleine Levin Syndrome. It is a closed group so that those dealing with KLS can feel comfortable talking to

others. Those friends I have made all over the world are a source of support that I could not get through this without. We are a small group and while I have never actually met any of these people they feel like family. Unfortunately, our family seems to be growing as more and more people become aware of KLS. I say unfortunately because this syndrome is so devastating that we all hate see another young person suffer with it. Fortunately, we are getting word out so those that have been misdiagnosed can finally have some peace of mind in knowing what they are dealing with.

Since the day Mikayla was diagnosed with Kleine Levin Syndrome, I have wanted to take her to Stanford University which is where they do research trying to find answers and a cure for Kleine Levin Syndrome. There are some amazing doctors there, one of which I have secured an appointment with. I have to get Mikayla to him to try to give her a better quality of life. She is such a talented and amazing person who is a ray of sunshine to many. Shes social, loves life, and loves all people. She stands up for the underdog and well, shes my daughter Im a bit partial. *insert laugh* We do not have the means to make such a trip, which is why it has not happened already. Mikayla wants to tell people about KLS. The more that know the more that will get properly diagnosed and the more understanding that will come from educating others.

Please tell others. Educate them. Get people talking. The more that know the more that the scientific world is going to have to care and feel pressured to do something to help all these amazing young people! I hope you and yours are doing well and God Bless you for your time

For more information or to make a donation to help us get to Stanford – then please visit:
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