



## 'Her Story'

*(As told by Jeanette K. Regnier)*

Installment Twenty Nine (August 7, 2006)

I was given two very meaningful gifts within the past few weeks.

The first present means so much to me personally.

My hairdresser presented me with a tongue depressor in a wrapper.

She told me how she and her son were downtown at Children's Hospital as her son was waiting for a test. Of course he became bored so she had him find a little something to "lift" from the room. This young man was told Emily's story as he waited. The wrapped up depressor was a wonderful gift because I knew Emily was still affecting people who were in the uncomfortable position of waiting in a clinical cell for someone to tell them they are fine-or not.

Second was a lunch date with one of Em's bridesmaids. Kathy lives so far away and she and Emily managed to be so very close. I never knew how the two met and I was delighted to hear the story from Kathy herself. Kathy is having some health concerns due to the radiation she had received as a young girl, but I believe she will be blessed with good health at the end of her current ordeal. Kathy was to attend camp for the first time, as a counselor.

Her Mom dropped her off and she was in the middle of no-where and did not know where to go. She had all her belongings and seemed confused when she happened upon Emily. Kathy asked her if she was in the right place and Em said "sure you are, where's your stuff?" and Emily took her car down to pick up Kathy's things and proceeded to tell Kathy just how much she would LOVE camp and all about the kids. In Kathy's words, "I was hooked (on Emily) after that"!

So, on to the surgery, the open laparotomy.

It was a very cold day on January 2004. Matt and Em and I woke up very early and made the trip to Ann Arbor to the hospital. Emily was to undergo a biopsy of the abdominal lymph nodes. Dr. Deihl, the surgeon, said this should take one to two hours, tops. Emily had been very busy since the nodes were sighted. A bone marrow biopsy (never watch this procedure if you don't have too), a PET scan. Lots of blood work, and another CT scan. The surgery got started early and Matt and I settled in to wait. Emily was never very concerned about going under general anesthesia, I guess because she did it so often.

Matt's parents showed up to lend their support. We sat, and sat. I paced and wondered, as I always did; What are they doing to my daughter back there?

Matt has nerves of steel and I always have envied him for it. I react, he acts. He was much better for Emily on most occasions that I was. Unless she truly wanted something done, in that case, I was easily ired and ready to battle for her in ANY way necessary. We waited, I paced. It wasn't long after the second hour passed that Matt began to wonder. He asked at the desk and was told they were still in the O.R.

Four hours later, Matt and I were summoned by the surgeon to a private place for a discussion. What she conveyed to us, still boggles my brain and makes me just plain nuts. Dr. Deihl claimed that it took her so long because she could not find a single enlarged lymph node to remove for biopsy. None, just tiny ones and not the evidence indicated on the CT scan. Four hours of digging around in my daughter's abdominal cavity, for nothing. We still have no idea what the problem was as a subsequent scan showed the nodes clearly visible.

The doctor was visibly upset by the fact that she was unable to recover any lymph nodes for the pathologist to examine. Dr. Deihl told Matt and I that most of her time in the operating room was spent trying to locate these nodes and she was concerned about giving up. According to the surgeon, she just did not want to give up and have to disappoint Emily with a major surgery that would not yield any answers for her.

Emily was sent to the surgical floor after the operation many hours in recovery. Em awoke long enough to convince Matt to go home to our house and be with his baby. I agreed to stay with her, hoping she would be out for the night, but that never happened. Once back in her room Emily was in some of the worst pain I had ever seen her endure. I called for the nurses' whose hands were tied. They could only administer medication per the surgeon's orders. Hours later, still screaming in pain, I demanded to see "pain management," a team of people who were there to control pain. Since Emily was allergic to so many opiates and synthetic pain relievers, it was a struggle to get the hospital personnel to understand that she must be given something more unconventional. The evening hours ticked by and I was in no mood to watch my baby suffer. I continued to call, page, or hit the call button for help. After 9 hours of horrendous pain, the surgeon responded and wrote orders for Em to be given fentanyl at whatever dose finally made her comfortable. Surreal and difficult! Ah, rest of her pain weary body. Finally!

It took Em five weeks to recover from the invasive surgery that led us to no where. Wow, did she suffer the consequences of that surgery, unable to care for herself at all for days after she was finally released from the hospital.

Emily recovered here and Matt worked when he could, obviously, he wanted to be here with his wife and baby. We let him decide what he needed to do and Emily pushed him to care for their house in Sturgis and the boss who treated Matt like a son.

From this day forward, Emily tried to recoup and get back home to her sweet house in Sturgis. Sometimes, she would succeed for a few days at a time but the pain was unrelenting. Months ticked by and more tests here and there.

Still nothing concrete to say that she had indeed relapsed, just the sickening feeling that lived inside my belly. Emily kept living the best way she knew how. A little at a time and with help all around her. She was enjoying watching her baby grow and learn sign language that she taught her so Cece would not be frustrated and able to communicate what she wanted and needed. It was like eating a big chocolate cake with fudge frosting- rich and sweet to see this mother and child interact.

But as the months went by, Emily found herself frustrated by the constant pain. She was ashamed that there appeared to be nothing wrong with her. At least nothing that was diagnosed. She wanted to make Matt a meal, clean her house, play with her baby. But every single day was hard for her. She wanted to feel "normal" but Emily could no longer recall what that word meant for her.

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