

Chapter 11

The Turning Point

*"We cannot direct the wind
but we can adjust the sails." —Author Unknown*

June 11, 1:10 pm

She's sleeping now. Oh, how sleep has become our refuge, a safe place to escape from this all-consuming world of cancer. I gave her some aspirin at 11am. Her temperature seems to have broken. To me, she seems listless and cranky, but she hasn't complained that she feels sick yet. "How do you feel, Amber?" "Good." And each time she says it, I am still amazed.

In the past couple of days, the metastasis that was there when we left the US, then shrunk as she began Burton's treatment, seems to be growing again. It spread to the other side of the surgery scar and toward her ear. Although it doesn't hurt when I press on it, that doesn't mean a thing. I remember the first lump didn't hurt her either. I must make an appointment with Dr. Clement as soon as possible.

She's getting tired of the injections. "I'm gonna run away from this place!" I can't blame her. I wish both of us could run fast and far away, leaving it all behind. Despite her frustration and increasing apprehension, she's been incredibly strong and courageous. "You know, Mom, I'm afraid when you put the 'Good Guys' in, and they won't do anything, and the 'Bad Guys' will eat me up!" What a hideous thing to face at four years old! I remember that age. The world around me appeared as though it was magnified a thousand times. Everything is huge: Feelings, events, images, fears. We feel so tiny, helpless, and at the mercy of those around us.

I had Dr. Clement examine Amber. She had a slight temperature and her tonsils were swollen. "Tonsillitis," he said each syllable slowly and with a hesitant caution. I knew what this meant. "So cancer isn't the *only* thing her body has to fight; now it's tonsillitis, too." The metastasis was growing again. I know Dr. Clement didn't want to worry me, so he didn't say it; he didn't have to. By now, I could see his diagnosis in his eyes. He prescribed Amoxicillin and tried his best to reassure me.

Her morale was sinking fast. She was tired, discouraged, and ready to give up. Though both Gary and I did our best to make a game of the therapy or treat it matter-of-factly, we were running out of ideas... of ways to help her cope. I mentioned this to Arla and she spoke with Dr. Burton. He offered to give Amber a couple of mice from his lab to keep as pets. Hopefully, they would raise her spirits and give her a reason to go on... to endure the numerous blood pulls and shots.

Dr. Burton had increased the therapy from one blood pull and four shots to two blood pulls and eight shots every day. He wanted to monitor her immune system more closely and arrest the small metastasis that now grew under her scar. Though it flattened two weeks after our arrival, it had now returned. I forced myself to stay in the present and NOT look forward. The future was bleak at worst, uncertain at best. "Now" was all we had and so I immersed myself completely in it.

June 12, 9 pm

While we were at the clinic this afternoon, Dr. Burton took us into his lab and showed us the mice that he uses for research. Row after row, containers of mice filled the room. I was surprised at his sensitivity. He reached into one of the cages, captured a tiny mouse, and turned to Amber. As he placed it on the floor, he said, "See how this baby runs when I put him on the floor?" He scooped it up, put it back, and chose another, a larger one this time. He placed it on the floor. It didn't move. "The adults won't run; they're immobilized. They've learned the limits of the cage."

I can see that he truly cares for Amber and he knows that she is discouraged. "Do you want to take some home?" "Really? Oh... yes!" She clapped her hands with joy. Burton was touched. "After you have your blood pulled tomorrow morning, come back here and I'll have two of them ready to take home." That's all she's been talking about ever since.

This afternoon while I was shopping at Winn Dixie, I met Mary Hofbauer. Her son, Joey, is seven years old and has Hodgkin's disease. Apparently, Joey's story has been all over the newspapers; his story parallels Chad's. After the diagnosis, the doctors had a protocol meeting with the Hofbauer's. Although the family gave them no reason, the doctors stated that they would take "strong action" if they didn't "go along" with the protocol. Mary agrees that this situation is unfair. Parents should have the right to choose whichever cancer therapy they feel is best for their child as long as they have carefully researched all of the therapies and protocols.

The bout with tonsillitis was beginning to take its toll. The metastasis was stabilized at 2 cm. Part of it had turned purple. "Necrotic," Burton said. Her hair was stubby now; I prayed that soon it would cover the tumor site and help me pretend she was healthy, *not* battling cancer. The growing tumor and nearly bald head were the physical symptoms; the ones inside were harder to see.

Amber was doing her best to continue the fight. She had her days of feeling low, but she expressed herself differently than an adult would. She could not identify, then explain what she was feeling inside. When she was tired, she got cranky and then her bad feelings came out. Most of the time, she handled her struggle the way a saint would; she rarely complained. When I asked her, "How're you feeling?" Her answer was always, "Good." Putting myself in her place, I would've given up long ago.

I decided to interview Amber since she was getting such a kick out of watching me interview the other patients. I thought it might be a fun and round-about way to find out what she was *really* feeling, without probing too deeply.

June 18, 1 pm