

Chapter 8

Welcome to "CancerWorld"

"Obstacles cannot crush me. Every obstacle yields to stern resolve. He who is fixed to a star does not change his mind." —Leonardo da Vinci

At last, my anger was released and with it, a flood of tears. I turned to Michael with a vengeance. *"I knew it!!! I KNEW IT!!! WHY DIDN'T YOU BELIEVE ME???"* His silence was deafening as he sat in the chair dumbfounded. I thought of ME and nobody else. I pressed Dr. Touloukian for answers. *"Why didn't they diagnose this sooner??? Why wouldn't they biopsy it?!?! They said, 'It can't POSSIBLY be cancer.' Why..."* He fumbled through the answers trying, but unable, to ease my pain and anguish. As much as he wanted to, he could not commute the sentence. Our eyes connected in some awful space—his full of pity, mine full of rage. He apologized again and again, then quickly backed out of the room.

I lost it. Crying uncontrollably, I screamed at Michael. *"No big deal, huh. Why didn't you believe me??? How can you NOT care about her??? You don't care about anyone but yourself, you selfish bastard!!!"* I didn't want to hear his defense; I was sure he'd scramble to find one. I left the room. I needed to find a safe place to explode... to release all of the pent up outrage at the "Medical Establishment," the animosity toward Michael, the anguish at what was, and at what was to come. My escape was in sight.

"The Laundry Room." I aimed myself in that direction. Hoping it was empty, I burst through the door and collapsed in the corner to cry until my tears ran out. I needed to calm down and empty myself so that I could make room to absorb this blinding reality.

When I was drained, I began to fill myself up with "pep talk." "O.K., Patti, Amber is *still alive*. *She isn't DEAD*. *You can fight for her*. Don't give up. You are all she has and she needs you *NOW!*" I snapped out of my daze, lifted myself up, and splashed cold water from the sink on my face again and again. With each jolt of the cold, clear water, I strengthened myself... I restored the energy and power that had just been stolen from me. I took a long, deep breath then braced myself and grabbed the handle of the door. Slowly and deliberately, I opened it and walked through. I turned in the direction of Amber's room. I knew she and Gary were waiting. Pushing myself forward, I took the first step and then many until I got closer. Picking up the pace as I neared the door, I switched back to my "outside" self—the Patti that was strong, capable, confident, and calm.

Without hesitation, I pushed open the door to our room. Gary was playing *Chutes and Ladders* with Amber. Michael had gone. I looked at Gary. Instantly, he, too, knew the truth. "C'mon, Gar, it's your turn. Oh hi, Mom. We're playin' 'Chutes and Ladders' and *I'm winnin'!* Wanna play?" "Oh... that's okay. You guys go for it. I'll just watch." I was now an active observer and dug deep into my soul to find the joy in the game... to ease Amber's painful experience and celebrate their fun.

Later in the day, I met with Diane Komp, Chief of Pediatric Oncology. She explained what rhabdomyosarcoma was and gave me a book to read, *Cancer in Children: Reason for Hope*. I turned to the index and looked for Amber's cancer. "*Rhabdomyosarcoma of the head and neck, in children, is usually a relentless, progressive tumor, which results in the death of a child in a relatively short time. Origin of the primary tumor in the head and neck, is much more common in children than adults.*" Amber was napping. I went out into the hall and cried. "My God... *this* is 'reason for hope'? Did Komp or Dewitt actually *read* this book?"

Our "Prognosis/Protocol Meeting" was scheduled for the next day. Dr. Chen, a radiologist, Komp, Dewitt, Michael, Gary, and I sat around a table in the middle of a very small room. As they spoke, the room began to shrink. Amber's prognosis: She had very little chance of surviving this cancer and only if we caught it

early on. We didn't. It had grown substantially through the months.

They explained. "There are four stages of cancer... the first stage is the beginning, the fourth stage is near death... Amber's in the third stage. Rhabdomyosarcoma of the head and neck in children is *extremely* rare... only two cases have been reported in the last two years." On and on and on they went. When one dropped the ball, the other picked it up. They rattled off figures and data and ratios. "Is this supposed to make me feel better?" I thought above the chatter, "Are these people *real or robotic*? Amber is a *person*, not a *number*. If they're so right, why didn't they know it was cancer *before* they opened her up? Why did they refuse to biopsy even when I pleaded with them to do it?"

Next came the protocol: What they intended to do about it. "Radiation to the head and spinal cord... chemotherapy..." "What will happen to Amber because of this treatment?" "She'll probably get nauseated from the chemotherapy and over a period of years, her trunk will be stunted three or four inches from irradiating her spine." Sarcastically, I thought, "Oh is that *all*?" They planned to do more testing to see if the cancer had spread: A spinal tap, radioactive liver-spleen, bone scan, miscellaneous blood tests, x-rays, and a CT scan. After they learned the results, they'd have a better idea of exactly where we stood. We'd have to stay in the hospital for a few more days.

In the afternoon, some students came into our room. A resident was explaining Amber's case. Cold and clinical as if Amber was an object... a thing, he grasped the drain to show it to the others. He told me he was going to remove it. "Doesn't she need an anesthetic?" "Oh, no, it won't hurt." He ripped it out. Amber screamed, "Ow... ow... Mommy, it hurts!" She started to cry. "How would you like it if I did that to *you*???" I glared. He was insulted. I pushed my way past the students and took her in my arms to comfort her. "Why don't you all just leave." I wanted them and the cancer to go away and never come back.

The next few days were spent going from one floor to another. Tests, tests, and more tests. Another room, another machine, another technician. More pain. I stayed at her side always. Although she seemed to radiate confidence, I knew she

was scared and tired of the pain. "Mom, can't we just leave now? I don't want to get another test. *Please!*" she begged. "Soon it will be over, Amber. I promise. Soon."

As we waited for Amber to get a spinal tap, I looked around the Waiting Room. Since we were rather isolated on the third floor, I hadn't noticed that there were a lot of sick children; some were bald, others were pale and weak. "God, this is bigger than I thought." I wondered how many more children were going through the same thing. Like cold water on my face, I heard her name. "Amber Calistro?" I snapped back to reality. It was her turn for torture.

We walked into a small, sterile room that was filled with stainless steel instruments of pain. Amber squeezed my hand. The doctor and a nurse came in. He advised me to leave the room. "I want to be here for her." "It will be worse for her to see you standing here unable to help. It should take about thirty minutes." Amber begged, "Mommy, please don't leave... *PLEASE!!!*" She was on the table now, groping for my hand. The nurse was holding her down. I felt physically bound to her and painfully pulled away. "I'll be back, honey... I *promise*. I'll go get some presents for you. I love you, Amber. *I love you.*" I backed out of the door. "Mommy... Mommy... *PLEASE!!!*" My heart was breaking as the door closed behind me. I turned around and ran.

All the way to the end of the hall, I could hear her begging me to come back. I ran to the gift shop without stopping. It was in a new wing that was built on the same footings that, only a few months earlier, I worked on as a laborer... I worked to make our life better. The irony did not slip past me but I didn't have time to indulge my thoughts. I needed to focus on now.

Just a shell, not a person, I frantically searched the shelves for trinkets to ease her pain and my guilt for leaving her. I felt empty inside. The real me was still in that room with Amber, suffering right along with her. Tears poured down my face and I didn't try to stop them. People saw me and wondered, wanted to ask, but left me alone to grieve. I was glad for the isolation as the pain was so great that any words would be like salt on a wound.

I raced back to the room and got there just as the spinal tap was over. Her eyes were puffy, her face was red, her voice was

raspy. She looked like she had been through hell. I swept her into my arms. "I'm sorry, Amber, so sorry. I wish I could protect you from this." Whatever happened in that room, was more than she could endure and I knew it. I wished I'd held my ground and insisted on staying by her side throughout. I would never leave her again. Never.

Friday, the results from the tests were back. "No other metastases... the cancer bore an eighth inch hole in her skull... there were a few suspicious cells in her spinal fluid." The Lump—the *cancer*—was gone, or at least this was my hope. "How did she get it in the first place?" I wondered, "*How? She's just a child.*" I combed through our history together and made a mental list.

- "From the beginning of my labor, the doctor who delivered her seemed to be in a hurry. He used forceps to literally yank her out of me. I could feel the pressure of him pulling... pulling *hard.*" I remembered her baby picture, the one they took just after birth, and how her right hand seemed to be holding the exact place on her head where the tumor was... where the forceps grabbed hold of her head. "Could the pressure of the forceps create such trauma that her 'embryonic cells' would develop into cancer?"

- Stress is known to have incredibly negative effects on the body, including the release of cortisol, which triggers our "fight or flight" response. "Did Amber internalize my and Michael's destructive relationship? How did Michael's apparent rejection of her affect her health?" Although she never mentioned it, I began to wonder.

- "Maybe it was that foreign object that got lodged in her cheek at St. Joseph's nursery school while we were living in New Jersey." I asked her about it. "Amber, what's this in your cheek?" She couldn't tell me and I never did find out what it was. Shortly afterwards, she began to have low-grade fevers and was constipated. The doctor said that her body would just absorb *whatever* it was; it never did.

- "Is it possible that all of the asbestos I breathed in while working at Glass Instruments had a hand in her cancer? After all, I *did* conceive her while I was working there." My mind was searching for a clue.

- "Maybe the fact that I continued to smoke throughout my pregnancy actually *gave Amber cancer!*" I shuttered to think it was *me*. I remembered bringing her to my meetings of the "Five Day Plan" when I quit smoking. She was just a newborn, in her car seat asleep at my feet when I saw that movie of a mother dying of cancer and the little girl wondering why.

- "Could Michael's punch to my stomach, while we were living in Long Beach, have damaged Amber or 'set the stage' for her cancer to develop?" I shuttered to think that her *father* may have caused her cancer.

- The area we lived in northern New Jersey with Aunt Anne and Uncle Bill had a huge number of cancer deaths. "Could she have gotten cancer from the water? Or food? Or their home?"

I wanted... I *needed* to find someone or something to blame, to hate as much as I hated this cancer and what it had done to my little girl who was innocent and pure.

We left the hospital that afternoon. God, it felt so good to breathe the fresh air. She was very weak and couldn't walk, but she was alive! My first job was to build up her strength with *real* food, not the dead food full of chemicals and preservatives they fed her in the hospital. Gary went to the health food store and got all her favorite goodies.

We settled her into our room at Bambi's. Everything she needed was brought to her side. This was Amber's "control room." I was grateful that she slept a lot of the time; sleep kept her from feeling any pain. When she woke up, she complained, "Mom, my head hurts." My heart went to my stomach. I gave her some baby aspirin and lay down next to her, rubbing her back and singing. I catered to her every need, gave in to her every wish and command, and spent every waking moment trying to erase her trauma and pain. I felt so helpless, despite all of my efforts. There was very little I could do and yet I was the only one who could save her. "God, please point me in the right direction. Please show me the way."

I was determined to deal with this monster and dedicated to saving my daughter's life, but I didn't know anything about cancer. I didn't even know kids *got* cancer. I was ignorant, afraid, and alone, except for Gary. Arming myself for the battle ahead

was something I could do. First step: To know my enemy. I went to the library and checked out every book on the subject of cancer I could find.

Dewitt called. He wanted to know about the protocol. "We don't want to take a chance on a reoccurrence. We need to start chemotherapy and radiation as soon as possible. Can you bring Amber in tomorrow?" "I'm not sure... I'm just not sure about bombarding her body with poisons." He sensed my skepticism. "Why don't I set up a meeting with Dr. Komp?" "Okay."

In the meantime, I needed to learn. I felt as though I had no power because I had no knowledge about what was happening to my little girl. I stayed up all night reading my library books, as the personal computer and internet weren't even invented then. My resources were the library, friends, TV, and newspapers.

Gary and I drove to Yale-New Haven with Amber. We walked into the room. Komp, Dewitt, and Chen were ready with their arsenal of facts and figures and documents. We were not a team. It was a dictatorship and I was to do as I was told. They were convinced; *they're* way was the *right way*—the *only* way to save her. They tried their best to convince us, too.

After they finished their speeches on radiation and chemotherapy, I asked them, "Is this all there is?" Diane Komp answered. "Yes, Mrs. Calistro, this is all there is." "You mean, they can put a man on the moon, but they can't cure cancer? There's *got* to be more than *this!*" I simply could not believe there was no other way and found it impossible to trust them. As they fumbled to make a feeble attempt to sell me, my thoughts echoed my "Mother's Instinct." "If they fed her junk food to help her regain her strength, wanted to use poisons to kill cancer and *normal* cells, and wouldn't believe me when I told them it was cancer *FOR SIX MONTHS*, how can I just blindly follow their advice *now???*" I pacified them. "I need to think about this."

I left the hospital convinced that there *had* to be more and dove head first into researching other cancer therapies. Knowing that those suspicious cells might be growing... spreading, I agreed to let them give her radiation to her skull. I had to do *something* and decided on the lesser of two evils presented to me: Radiation and chemotherapy. The race was on to save her life. Quick