

## Chapter 9

# *Underground Escape*

*"Hope is both the earliest and most indispensable virtue inherent in the state of being alive. If life is to be sustained hope must remain, even where confidence is wounded, trust impaired."* —Erik H. Erikson

I wanted to stop bombarding her... to leave her alone and let her live her life the way it used to be—no pills, no radiation, no doctors, no pain—but that would mean watching her die. I simply could not do that. As her mother, I gave life to this child and I refused to let it slip away without a fight. Besides, I'd noticed a remarkable change in the past two weeks. She went from crawling to running, whining to laughing, and sickly to... well... as healthy as she could be and still have cancer. "Maybe the alternative treatment is working," I prayed.

Along with her renewed strength, she began to assert herself... to take control. After all, it *was* her life even at four. She knew how important it was to go for radiation treatments, follow the diet, and take the pills, but *she* had the power to live or die, not me. If she didn't want to do any of it, she wouldn't. "How can I blame her? How can I force her? Why would I want to if the outcome was the same?"

In my quest for cancer information, I combed the bookstores and libraries. I came across "*Choices*," a book about cancer, therapies, and the choices that are available. I was hungry for information and would not be satisfied until I devoured every last bite. Since Amber was asleep for the night in our room and Bambi was in hers, I went into the living room, made myself comfortable, and began to read. I quickly looked up "rhabdomyosarcoma."

*Chapter 20, Childhood Cancer, Tests for Childhood Cancer:*

*X-rays*

*Angiogram*

*Intravenous pyelogram*

*Cytoscopy*

*Brain scan*

*Biopsy*

"Biopsy!" The word shouted from the page. I was shocked. The preface was written by Joseph Bertino, MD, Chief of the Section of Medical Oncology and the American Cancer Society, Professor of Medicine and Pharmacology at... *what?...* YALE SCHOOL OF MEDICINE! "Yale had this information and they didn't do any of these tests on Amber? Even the night before surgery, when the tumor was huge, they told me, 'It can't possibly be cancer.' What *do* the doctors actually *know*?" I had no idea where to look or where I could turn to find the truth. The medical world I grew up trusting, came crashing down around me. I calmed myself down and read on.

*TYPE: Rhabdomyosarcoma*

*AGE: 2-6*

*SYMPTOMS: Swelling, bleeding, unusual mass ("What?!?!") found in the head, neck, eyes, genitourinary system, extremities, chest, and abdomen.*

*TREATMENT: Surgery, followed by chemotherapy and radiotherapy. High cure rate in the early stages. ("EARLY STAGES... why didn't they believe me?")*

*WHAT IS RHABDOMYOSARCOMA? This is the most common ("Most common?") soft tissue cancer among children... it occurs most frequently between the ages of 2 and 6. Symptoms depend on where the tumor is located.*

*HOW IS RHABDOMYOSARCOMA TREATED? Treatment depends upon where the tumor is located and the cell type. Since this cancer is highly malignant, ("She's going to die.") the stage at which it's found is an important factor. Metastases occur early, and often spread to distant organs, generally, the lung. Biopsy is usually performed to establish diagnosis.*

I stared at the book through my tears and couldn't blink them away. It was a blur. I could not go on. My world was shattered. For the first time in my life, I couldn't bend down and pick up the pieces... turn this thing around... make it whole again. Perseverance and persistence were the driving forces that always helped me transform pain into power. But *this* was something I had never experienced: Utter helplessness and despair not only for me, but for my daughter

Words were sloshing around in my head: "Incompetence... liars... power-hungry... uncaring... selfish..." I could not make sense out of this at all. They *had* the information "in house" the entire time before and after Amber's diagnosis and surgery. They could also have gone to the bookstore, like I did, and bought *Choices* along with other books on cancer therapies, to get up-to-date on rhabdomyosarcoma and all of the treatments that might help. If they weren't sure, couldn't they look it up in a book... the same book that Diane Komp handed to me just hours after the first tumor was removed? All the answers, the tests and the hope, were there for the asking, yet no one bothered to do it. It was up to me, not them. I took their ignorance to heart and continued on my quest for a cure.

Anger was bubbling up and I couldn't deny it. I was right all along but I didn't want to be. The memories came back: All the times I had tried to convince the doctors and the dismissive words they gave me in return. "How can I change the past *now*?" I thought. I cried for a long time. And then I was enraged. "Dammit, God! Why have You done this to me... to Amber? I've been good... I *am* good and so is Amber! Why didn't You choose somebody else? I WANT OUT! I WANT MY LIFE BACK! I don't want to go through this anymore!!!" I was furious at God... the doctors... Michael... at anyone, at *everyone* who had ever treated us badly. I broke down, sobbing out of control, hoping my plea would provoke a miracle... hoping I wouldn't wake Amber and Bambi.

On April 14th, nearly three weeks after the surgery, we drove to Long Island for her first "cocktail" with Dr. Cole. After a brief wait, the nurse led us to a back room—the Treatment Room. It was small, about 10'x14', and lined with brown reclining chairs

on both sides of the walls. There was a row of windows at one end with a door at the other. It had white walls with nothing on them. It was unremarkable except for the people. *It was filled with people.* Each one was hooked up to an IV bag, which hung on a hook next to their chairs. Some had the needle in the top of their hand, others had it in their arms. All of them chatted like long lost friends.

The moment we walked in the room, they stopped talking. At once, all of their eyes looked up at me, then down at Amber. "*A child!*" their collective thoughts said. They were surprised, saddened, touched. She quickly scampered over to the empty seat and sat down with her little stuffed dog. She brought him along to get a "cocktail," too. I greeted everyone, introduced myself and Amber, then sat down, lifting her onto my lap.

The nurse explained that she would be given an IV; it would take about 45 minutes to empty the bag. I could feel Amber starting to squirm and tried to distract her with the cassette tape and book of *Pete's Dragon* we brought. We were reading along in the book when the nurse wheeled over the IV. "Now, honey, you'll feel a pinch right here," as she pointed to the top of her hand, "but it'll be over in a second." She took out the swab and cleaned her hand. I held her arm. Ever so slowly, the needle poked through her skin. "OW! MOMMY! OW!!!!" No vein. The nurse pulled it out and tried again, despite her shaking hand. She tried to steady it as the needle pierced Amber's skin again. Nothing.

Near hysterics now, her body jerked with each stab. She begged and pleaded, "Mommy, mommy, PLEASE don't let them do this! Mom??? PLEASE???" I was powerless. I could feel her pain throughout my body, but could not take it from her. She couldn't see me crying, as her back was toward me, but she *could* hear my voice trying to calm her, soothe her, get her to accept this agony. "I'm here, Amber... she's almost done... it'll be okay... it will, I promise." I was trying to convince everyone, including myself. Tears were falling down my cheeks and I didn't dare wipe them. I had to hold her... comfort her... pretend that everything was alright. I had to be strong for Amber.

The nurse left to get someone else to try and find her tiny veins. Everyone in the room was visibly shaken; they all had tears

in their eyes. They knew exactly what she was going through, but they were *adults*. They understood that they had cancer and they chose this form of therapy. It was heartbreaking for them to see a child be victimized like this. I wanted to protect her, heal her, save her, but couldn't. Helpless... we all felt helpless.

Another nurse came in and, thankfully, found her vein quickly. We dried her tears and sat back to listen to the tape and read along with the book. The time went by quickly. By now, time was surreal; it would fly or it would crawl. It no longer had the steady rhythm that it did before the cancer. Tick... tick... tick. Each second, minute, hour was the same. Days turned into weeks, into months, into seasons. Everything was different now, even time. Depending on the activity, our life was either a dream or a nightmare. Reality was only a concept, a memory that existed in my head, not in the world we were living each day.

By the time we got to the car, she was exhausted and slept the entire way home. It was difficult to drive; I just wanted to stop, relax, and watch her sleep. I carried her limp and weary body into our room, laid her on the bed, carefully undressed her, and tucked her in for the night. I stood back and watched her. "She looks so innocent. Why? Why is this happening to *her*, God? She's been through Hell. How much more can she take? Give her a break, God, will You?" If He was in the room, I would have slugged Him—even *HIM*—to release my rage and protect my daughter.

The Green's sent me a letter to let me know they cared and would be there for me. They also sent some valuable research information and a \$50 bill. "How did they know I needed this money?" I asked myself. I was grateful for their gift. They told me that homeopathic doctors were having good success with cancer patients. I looked up "homeopathy" in the dictionary. "*Homeopathy: A system of medical treatment based on the use of small quantities of drugs, that in massive doses, produce symptoms similar to the disease under treatment.*"

A few days later, Amber refused to take the "pill powder." "I don't want to take pills anymore! I'm gonna go where they won't give me pills!" I couldn't really blame her, but I couldn't let her know that. I didn't want her to get discouraged and give up. I cut

back on the dose and tried to reason with her. "Amber, *please*, this will make you well. *Please*." It was no use. After all, it was *her* life not mine. *She* would choose how to live, how to die, and when. "She's just four years old. She can't make those decisions." I heard this again and again. I began to see how much prejudice there was against children, especially children with a life-threatening disease like cancer.

As we approached the circular on-ramp to I-95 heading towards New York, Amber asked with suspicion, "Mom??? Are we going to get another cocktail?" I toyed with the idea of lying to, or tricking her, but decided against it. "Yes, Amber, we are." She had had enough. "No! I don't want another cocktail!!! I'm done getting cocktails!" The words were at the tip of my tongue, "But you'll die if you don't!" Instead, I searched for the words that would not scare, but convince her. "Amber, we need to get you better and this is the way to do that. You want to go back to school, play with your friends, and not have so many pills, right?" Quietly, she relented. "Yeah." "Okay. What tape should we listen to: *The Muppet Movie*, *Thumbelina*, or *The Little Engine that Could?*" With subdued resignation, she mumbled, "*The Muppet Movie*."

Several people recommended that we see Dr. Joseph Kaplowe, a homeopath practicing in New Haven. When I saw his name on the list that the Green's sent, I called for an appointment. His assistant, Rosemary, told me to come at 7:30 that evening. Gary drove us. The office was located on a residential street lined with very large houses, dating back to the 1940's. We felt welcomed immediately. "This office is not typical," I thought, "It seems so warm and comfortable, more like a home than a doctor's office." Rosemary met us, gave us a brief tour, then talked with us for a while. I brought her up to date: "Cocktails" in Long Island four times a week, radiation to her skull every other day, the supplements, and her special diet. It was a lot for such a little girl.

She led us into Dr. Kaplowe's office: A large room filled with lots of books, magazines, photos, and certificates. "This man is well-read," I thought. There were plants everywhere. A distinguished elderly gentleman greeted us. He was slight with a full head of white, curly hair and a quiet, gentle manner. His eyes were kind and knowing. He spoke with us at length about Amber

—her diet, habits, personality, tolerance to medicines. During our conversation, Rosemary came in with the latest copy of the *New Haven Register* and held it up for us to see.

"*Mother Ponders Cancer Therapy for Child.*" There it was, right on the front page, along with our photo and a story. It explained Amber's journey with cancer, her experience with the doctors, and our predicament now: "How do we find a therapy that will cure, not *kill*, her?" It ended with a quote from me: "We were afraid that they (doctors) might think *their* way was best, even though they can't prove it."

Dr. Kaplowe had a twinkle in his eye and a smile on his face. I could tell he'd been through this "underground therapy" scene many times before. He wasn't deterred from his purpose: Do the best you can for Amber, regardless of the cost. He continued with our visit and described our options.

Dr. Lawrence Burton, who practiced immunotherapy in Freeport, Grand Bahamas, was his choice for therapy. He explained. "From good, healthy, donated blood, five protein fractions are extracted. Many protein fractions make up the immune system; Burton has isolated five. Then, blood is drawn from the cancer patient, analyzed, and the levels of these protein fractions are measured. Whatever levels are low, are then raised by injecting the cancer patient with the protein fractions that were isolated from the 'good' blood. This maintains the immune system at the optimum level to fight the cancer on its own." No poisons; it worked naturally with the body. Rosemary would contact Dr. George Beatty, Dr. Burton's liaison here in the states. It sounded good, but I needed to sort through it. "Can I call you tomorrow?" "Sure. You think about it and call if you have any questions."

As a result of the newspaper articles, we were flooded with letters, calls, and telegrams from around the world. I was unprepared. Since *The Associated Press* put it over the wire service, people around the world knew Amber, and all of them cared. "No one will let them take Amber from me. No one." I prayed that I was right.

"Have you heard of Dr. Burton... Kelly... Contreras...?" The list went on and on. Hundreds of scientists all over the world— not just in the US—were working on a cure for cancer and many

were seeing success. I was astonished at the number of people who were aware of other ways of treating cancer. "Why isn't everyone working *together* to cure... to *prevent* cancer?" I simply could not see the reasoning behind the apparent "close-mindedness" of the American medical establishment. "What is more important than this? Why isn't this information available to everyone?" I couldn't understand why I had to dig... why I had to go to the newspapers and publicly beg for information about cancer.

During our "Prognosis/Protocol Meeting" at Yale-New Haven just a few weeks earlier, they said there were only three cancer therapies available: Chemotherapy, surgery, and radiation. "Why didn't Yale tell me about *all* of the cancer therapies when I asked them, 'Is this was all there is?'" With certainty in her voice, Komp said, "Yes, Mrs. Calistro. This is all there is." I was incredulous! "What is going on???"

Though I needed to know the story behind the story, I didn't have time to dig further. My focus needed to be on Amber... on saving her life. I did my best to navigate through the maze of cancer therapies and ignored the politics behind them. I couldn't care less about the politics, not now. It was my first glimpse into the "cancer culture," or subculture, I'd suspected all along. In a matter of days, I was thrust into the underworld. I felt like I was a criminal living with other criminals and outcasts: People who had cancer and wanted another, less toxic way of healing themselves. I was now a member of "The Cancer Club," a private club in "CancerWorld" where you or a loved one searched for treatments and a cure. You had to have cancer to be admitted. I didn't want to belong.

I called Rosemary and asked her to set an appointment with Beatty. A few days later, we drove to Greenwich to see him. I opened the door to his office, but wasn't sure I was in the right place. The people inside were talking, laughing, sharing pictures. It looked like a family gathering. "Is this Dr. Beatty's office?" "It sure is! Come on in... Hi, I'm..." They went around the room introducing themselves and their cancer. "No way!" I thought, "These people can't have cancer! They look healthy and happy!" Instead of the dread, fear, and hopelessness I saw in the Waiting

Rooms at Yale-New Haven, I saw laughter and optimism. We sat down to join them and all talked openly about cancer. It was refreshing.

They had great respect for Burton, believed in his therapy, and eagerly told me of their experiences. Many had exhausted the traditional cancer therapies, been sentenced to die, and gone down to Freeport, Grand Bahamas, only as the last hope. Their healthy bodies before me were a testament to the effectiveness of Burton's treatment. My thoughts began to soar. "I walked into heaven and this is a miracle! Maybe Amber will live after all!"

"Amber? Come right this way." We walked into Beatty's Examining Room. He warmly introduced himself, then bent down to Amber's level to talk with her and put her at ease. He turned to me. "I've just gotten off the phone with an 'Angel.' She's donated \$3000, a thousand dollars a month, for living expenses. Burton will treat Amber at no charge." Those words came straight from God. I was stunned. I had to sit down. "You mean, we are going to Freeport and Dr. Burton will treat Amber for free? And we don't have to worry about money while we're there???" "Yes." He woke me up. It was true; it wasn't a dream.

He explained that we would have to find an apartment to live in once we got there, but the other patients would help us. He handed me a piece of paper with all the information on it; written across the top was "Arla Amara." "Ask for her as soon as you get to the clinic; she'll know what to do." He gave us a timer and a thermos. "You'll need to keep the syringes cold and time them an hour apart." I wasn't sure exactly what he meant, but at that point I didn't care. Amber was going to live, that's all I wanted to know.

Somehow, I drifted out of his office holding the supplies and Amber's hand, got into our car, and drove to I-95. This time, we were headed north to go home, not south to get more "cocktails." The traffic swept me up. We were moving along at a nice pace and, for the first time in months, I was truly happy. Then it hit me: "God's wrong. She's *not* going to die, she's going to *live!!!*" My joy had no limit. I felt as if I had given birth to her all over again. I pulled off the highway and hugged and kissed her. "Mom, what are you doin'? Is everything okay? How come you're so happy?"