

Chapter 12

Making Memories

"Things that are hard to bear are sweet to remember." —Seneca

July 20, 4:45 pm

I'm in flight. Amber is cuddled up in a blanket, fast asleep on the empty seats across from me. She's clutching her "Sheepy," a small white stuffed animal. As hard as it is to believe, we're on our way to Montreal! Doctors have agreed to de-bulk the tumor without forcing me to give her any additional treatment; no chemotherapy; no radiation. They respect my decisions as her mother. This is the first time Burton has asked foreign doctors to help him. Amber is now a "goodwill ambassador." Dr. Burton has gone way beyond any hope or expectation. He's paid for everything, even giving us \$1000 cash to "have the time of our life!" David Stewart is covering the hospital stay and all tests. Oh, God, I am so grateful.

We will arrive a JFK at 5:30pm, catch Air Canada at 7:40pm, and arrive in Montreal about 9pm. The Stewarts are supposed to pick us up at the airport, take us to The Royal Terrace Hotel, and then to the hospital in the morning. Another journey... another chance to live!

While Amber and I flew to Montreal, Gary stayed in Freeport to work at the clinic. He was enjoying his work in the lab. It made him feel as though he was not only actively doing something to help Amber, but making a difference in the lives of all of the other cancer patients as well. I admired his willingness to set aside his life in the States and support us, but I knew it was taking its toll. Gary missed his son, his family, and living a normal

life. The only way to cope with our life in the Bahamas, was to "live in the moment" every day, not look too far ahead, and do what we could to ease the pain of others.

Flying to our "Beacon of Hope" was overwhelming, but exciting as well. It felt as though we were in the eye of a hurricane; uncertain we were safe, yet hanging on to the hope that the storm would pass over us without damage. We'd come so far and needed to enjoy the little bit of peace and serenity that the "eye" allowed us. I knew that wishing couldn't make it so and was certain that the calm was only temporary.

Since I'd never been to Montreal, I had no idea what to expect. Though Canada was our neighbor, I knew that the culture would be different. Navigating our way through their medical system would be a challenge. Having David and his assistant, Claire, to guide us would be a godsend.

The plane from JFK was nearly empty. I settled Amber down across the seats in front of me; tucking her blanket around her and her "Sheepy" that she brought along on the adventure. She was exhausted and immediately fell asleep. I sat back to relax, have a drink, and bask in this brief respite. "The letter." I took out the letter that Dr. Clement wrote to the doctors in Montreal.

To Whom It May Concern:

Amber Calistro is a four-year-old with rhabdomyosarcoma of right post auricular region. Excision-biopsy was carried out by Dr. Touloukian at Yale-New Haven Hospital, New Haven, Connecticut. This was followed by approximately 2,000 rads to the head and neck.

Amber has been in Freeport since 13 May 1980, receiving Immuno-Augmentative Therapy. This treatment has resulted in great improvement in her blood immune assays, but also a slow increase in a recurrence at the tumor site.

We are presently interested in obtaining help to de-bulk the tumor with minimal trauma to the surrounding tissues. Our results here, show that if a tumor can be dramatically reduced in size, it is likely that Immuno-Augmentative Therapy will contain any further occurrence.

I apologize for not addressing this letter in person, but Mr. David Stewart will probably have approached you on this subject.

*Enclosed is a copy of all of Amber's records since her arrival here; the other results from Yale-New Haven are held by Amber's mother.
Thank you very much for your help with this delightful child.*

Sincerely,

John Clement, MRCS, LRCP

We arrived on time. After collecting our luggage, we waited in line to go through Customs. It was late and I was nervous. I looked down at Amber, a bit sleepy and clutching her little stuffed dog that she sometimes used as a pillow. We inched closer to the customs officer. I caught my reflection in the glass. I didn't know the person looking back. I was skinny with sunken and tired eyes. "Next?"

We went into the Customs Office. "Good evening. Welcome to Canada. What is the purpose of your visit?" "I'm bringing my daughter here for tests." "Tests?" "Yes, she has cancer." "Cancer?" "Oh no, the whole discussion is about to begin," I thought. "Yes, she's receiving therapy in the Bahamas and we're here to test her for possible surgery." They seemed confused, so we spent a lot of time going back and forth, checking papers, letters, etc.

I was tired and just wanted out. I wanted to crawl into bed—any bed—and surrender to sleep. I needed to let go of reality, if only for a few hours. My mind drifted off as he said, "You can go now. Enjoy your stay." He motioned toward the door. I snapped out of my thoughts, thanked them, took Amber's hand and headed out into the night.

22 Juillet, 3:30 pm

Ah yes, Montreal! It's so exquisite, fancy, old, delicate... so French! We spent the first night at The Royal Terrace. Amber was exhausted but fine. She is off Burton's therapy which frightens me. For the first time since her diagnosis in March, she isn't on ANY therapy. "Will the tumor spread... start to cause pain... open up and bleed... what?" For her, it will be a needed break; no pills, no shots, no pain, no clinics filled with people

who have cancer. For me, it will be a gamble, a chance at risking her life now, to save it in the future.

The next morning at 9:30, David Stewart picked us up and took us to the Hospital Sainte Justine. We went through admissions, then up to Etage 5, room #5223. After we got settled, a nurse came by and took three vials of blood, a coagulation test, and a urine sample. It feels strange to stand by and watch someone else draw Amber's blood; though I'm glad to be on the sidelines for once.

Most of the people at the hospital speak only French. I knew the three years of French I took in high school would come in handy someday. I brought along my English-French dictionary for reinforcement and figure I'll do my best to communicate.

Compared to the constant blood pulls and shots, our stay was very pleasant. We had three meals a day, a television in our room, and a playroom at the end of the hall. Our room was large and bright with windows that overlooked a park. We even had our own private bath and shower. Amber's hospital bed was similar to a big stainless steel crib with sides that went up and down. I slept on the couch that was next to it, glad to be at her side.

For the first couple of days, she went through a barrage of tests. As I stood outside the Radiology Department, I overheard Dr. Blanchard discussing Amber's case with his assistant. I tried my best to interpret what they were saying. Basically, they were concerned about the possible involvement of the mastoid area. "The tumor may be deeper than we thought." He came out and spoke with me. "I'm not sure how deep the tumor has gone. We'll need to get a CT scan to have a better idea. Even though I, myself, don't believe in Immunotherapy—at this point, anyway—everyone has their own beliefs and I can certainly respect yours." I got the feeling that the Canadians didn't feel threatened by the so-called unconventional cancer therapies.

22 Juillet, Midnight

After I tucked Amber into bed and stroked her to sleep, I went for a walk. I knew she was overtired and would sleep for a while. I needed to get out... to see if a world still existed beyond the hospital. I walked across the street to the park. After it started to rain, then pour, I spotted a corner cafe and ducked inside. It smelled of coffee and pastries and cigarettes. I sat down at the nearest empty table and blended into the crowd. Alone among the strangers, I finally had a chance to think.

"Oh, Amber, it's so hard to watch you die! You are so pure and innocent. I'm terrified of the future. Right now you feel no pain... suffer no side effects, though the new tumor is growing. You play, sing, and dance just like any other child. At times, my pain is so great, I want to turn my gaze away from you, away from the cancer that sits on your head glaring back at me. I no longer put my "all" into us; that would be investing in the future; that would be more to lose. Can anyone ever begin to understand this pain I feel? It is a physical pain. It hurts so much I want to die! I want to go with you, Amber."

Our stay at Sainte Justine's was made easier by the staff as well as the other children on the floor. Many of them were gravely ill, but none of them were so obvious as Amber. The tumor was massive and too big to ignore. Despite its size, it didn't stop her from the simple pleasures of being a kid. She still wanted to live her life and live it the way she always did: Playing, laughing, doing all the things children do as they grow into adulthood.

One morning, after the tests were completed for the day, we went down to the playroom with our face paints. I'd done some face painting before and enjoyed it. I carried them with us wherever we went, just in case I needed to entertain some children at a bus stop, in a park, outside the grocery store, or in a hospital. The local Canadian children could not speak English, so they watched in fascination as I sat Amber down and began to transform her into a "princess." They giggled and laughed as I painted her lips bright red, put blue eye shadow on, and stroked delicate black lines under her eyelashes to exaggerate her own. "Okay, who's next?" All the children raised their hands. Amber became my assistant face painter and worked alongside me to brighten their day. Her occasional slip of the hand or smeared line

wasn't noticed as they scurried over to the mirror to see the new face looking back. Lions, puppy dogs, Dracula, and more than a few princesses filled the playroom with laughter.

On Friday, we took a taxi to the Hotel Dieu (The House of God) for a CT scan, a detailed series of vertical x-rays that would help us determine exactly how far the new tumor had gone... how much had penetrated *inside* her skull. I was concerned, yet confident, about the Canadian medical system. There seemed to be a true sense of teamwork... of pulling together as one for the benefit of the person who was sick... of a willingness to explore ALL options, regardless of origin.

The Hotel Dieu was an enormous, very clean, and modern hospital. As we went up to the Radiology Department, I glanced at the bronze plaque above the door. It told me that the CT scan machine was donated to the hospital by David Stewart. I asked the technician about it. "Oh yes, Mr. Stewart has given millions of dollars to help ill children." I was so grateful that he chose to help Amber and certain that God had a hand in it.

Dr. Mecina came into the Examining Room just as Amber had changed into the hospital gown. He explained to us exactly what he planned to do. "It won't hurt a bit, Amber." He walked us into the next room. "You'll lay down on this table, the nurse will put a 'hat' on your head, and then you'll hear some buzzing sounds. The only thing you have to do is stay very, very still, okay?" She nodded apprehensively and clutched her Sheepy tightly.

They took a series of eight pictures. Dr. Mecina reviewed them with me. "You see this area here? This is the tumor... here is her skull bone. I'm not sure if there is any involvement with the brain. Just to be sure, I'd like to inject a dye that will help us to see the images more clearly."

I went into the room and explained it to Amber. "It'll be just like a blood pull." The nurse came in with a very large syringe filled with 26cc of Renographin-60. She tried to find a vein in Amber's arm without success. "Do you want me to try? I've been pulling her blood a couple of times a day for the last three months." "Yeah! My Mom can do it!" The nurse hesitated, then consulted with Dr. Mecina. "Well, it's unconventional, but let's

give it a try." Amber relaxed. On my first attempt, I was into her vein. They were surprised and relieved. I was amazed at how well I knew her body, right down to her veins.

After the test, the nurse took Amber to get dressed while Dr. Mecina studied the images with me. "The tumor is about 1 1/2cm *inside* the skull." I heard a gasp; it was me. "The rest looks fine. If they *do* operate, they will take out the affected skull bone and replace it with acrylic." It sounded like he was describing the beginning of the end. Almost like "Frankenstein," she would be taken apart then put back together.

23 Juillet, 9 pm

Amber is sleeping soundly. She had another exhausting day. The results of the CT scan seemed like another death sentence. Before we got back to Saint Justine's, we went for a walk across the street in a field of flowers. I had such a feeling of doom and dread, as though this was our last walk before her sentence was carried out.

Like so many times before, I drank in every detail of our movie... of our life together. "Her hair glistening in the sunshine... her little pink dress... sandals... tan skin. I love the way her fingers gently caress that bouquet of flowers." She continued to pick the wildflowers, then stopped and looked up while she handed them to me. "Hey, Mom, ain't I the BEST picker?" "You are, Amber. You are the best!!!"

Tears were beginning to well up in my eyes. I tried to keep them from spilling over. It wasn't working. "Amber, I REALLY love you, ya know." "You don't want me to die?" she said. I was surprised. She could read my mind. "Do you want to die?" "No," she said calmly. The question didn't phase her. "Amber, what do you think happens when you die?" "Your spirit lives." "That's right. No, I don't want you to die. Have you ever died before?" "No." "I have." We walked on. Amber resumed her flower picking. I returned to my thoughts.

Since all the tests were completed, the conclusions were basically drawn: They would not operate. It would possibly do more harm than good. Dr. Blanchard let us come and go as we