

Remarkable story of a battle against cancer and ultimate recovery.

**Strength and Courage**

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## Chapter 1

On March 26, 1994 at about 4 o'clock on a Saturday morning, I awoke to the sound of our 18 year old son moaning, "Help me... someone help me." Barely able to get my robe on fast enough, I stumbled out of our bedroom to find Curt lying on the bathroom floor moaning and holding his stomach.

Nine days before, on St. Patrick's Day, Curt, six feet three inches tall and weighing 190 pounds, had been working a ski lift at a nearby ski resort. A skier had jumped hard onto one side of a two-man lift causing it to kick over and hit him in the abdomen at the base of his ribs. Curt had been in pain but refused to go to the doctor for several days. When he finally agreed to go he was told that he had bruised ribs and torn stomach muscles and he should take it easy for two weeks.

The job was coming to a season's end anyway, after which he was planning a trip to California before going into the Army in the fall. So with time on his hands sooner than expected, Curt had decided to visit his grandparents who live three hours away on a farm up in New York State. The mountain roads going up there were not very good, and his car seemed to exaggerate every bump in the road. This had made him feel worse, so instead of staying longer, he cut his trip short and returned home Friday night.

By the time I was able to get a doctor on the phone it was Saturday morning, more than a week since the accident, and Curt was having severe stomach pain and was bringing up bile. When I explained what was

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happening, the doctor said to rush him to the hospital. He would meet us there, as it sounded like Curt's spleen had ruptured. Since he hadn't mentioned an ambulance, I told my husband, Carl, and our daughter, Sheri, that we would probably be back shortly and not to worry about going with us. We just didn't realize how sick Curt really was or that the doctor felt it was faster not to wait for the ambulance which would have to come from eight miles away.

The fourteen-mile trip on our rural country roads seemed to take forever, especially since any bumps in the road only made him feel worse. When we finally arrived, rather than make him walk from the parking lot, I let Curt out by the door and quickly went to park. Luckily a friend happened to be there when I let him out since Curt collapsed on the way in. My friend, who was there to visit her father, got him a wheelchair and a nurse, and they took him directly to the emergency room.

After parking the car, I went in and registered Curt. By the time I got into the emergency room by him, the doctor said things were not good. They felt his spleen had ruptured and they were running tests and blood work before they operated. I called Carl to tell him what little I knew and to come to the hospital as quickly as possible.

Curt was worried that he would have to stay in the hospital and asked me not to leave him there. He had lost several friends a few months before due to car accidents, and felt that if he stayed in the hospital he would not come out either. In one of the accidents, three girls he knew were killed on the way home from school and Curt found them in the road. It had been pretty traumatic for him at the time.

While waiting for the x-rays and blood work results, Curt's blood pressure suddenly dropped drastically. When

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it hit 67 over 37, the surgeon who had barely left Curt's side, started barking out orders to add another IV among other things. Then things started looking even grimmer.

By this time Carl had arrived at the hospital. The surgeon brought us out of Curt's room to tell us that his platelet count was so low that if he attempted to operate on him in this condition Curt would bleed to death from the incision. Platelets play a major role in clotting our blood. We would soon find out just how critical a role they would play in his future. For now, we had to wait for platelets to be delivered from New York City. They would do their best to keep him stabilized until then.

When it came time to sign the paperwork for him to receive donor blood products, Carl and I both realized that he could receive blood tainted with the AIDS virus. The doctors warned us that at that time the testing wasn't 100% accurate. We really didn't have a choice, so we signed the papers.

We were also told that his x-rays showed a huge mass much bigger than his spleen should be. Between this fact and the low platelets, the doctor told us he wasn't sure what he was dealing with. He asked us if we understood just how serious this was. We said, "Yes." But looking back, I'm not really sure we did. After all, how could something terrible happen to our son? Bad things happen to "other people".

It was with a sigh of relief that we saw the man arrive from the Blood Bank a slow three hours later. As they wheeled him into the operating room, the surgeon asked if we wanted to kiss Curt good-bye. I didn't realize until a little later that he was telling us we might never see him again. Once again we sat down to wait.

Some time later the surgeon came out with a smile on his face to tell us Curt had made it through the

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operation. His spleen had ruptured, and it was enlarged, but that was not that unusual. He explained that normally it is the size of a fist and is roughly in the area below your left armpit. Curt's was several times that size. It was so large that it was down below his ribs, which is how it was exposed to the ski lift injury.

He went on to explain that quite often when a spleen is enlarged, it is a sign of certain types of cancer. Since the surgeon happened to be an Oncologist/ Surgeon, he was aware of this and would be sending the spleen to Pathology for testing. Other than that he hadn't seen any signs of cancer, although he had opened Curt from his ribs all the way down past his belly button.

Curt was placed in the intensive care unit for now. We were allowed to go see him even though he was pretty much out of it. Finally, since it was already about 8 o'clock in the evening, we decided to let him sleep. We said our good-byes and went home. Already disoriented from the way our day had gone, the trip home seemed strange. We had survived our children's' early years without any major catastrophes and had never left one of our children in a hospital before. Yet we were relieved that he seemed to be all right, and we were grateful that he had made it safely through the operation.

Shortly after we got home, we got a phone call. Curt had woken up and the nurses got him a telephone so he could talk to us. He seemed to know he was going to be all right, and we told him we would see him tomorrow. We explained to our daughter what had happened, and went to bed hoping the worst was over.

The next day they moved Curt out of intensive care to a regular room. He was sharing the room with an older gentleman who kept moaning, so Curt was not happy. He asked to be moved to another room, and later that day

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they put him in the Pediatrics wing where he had his own room. The prospect of having his own room made him happy.

Sheri, a high school junior, and her boyfriend, Don, came to visit. Later, we found out that the doctor who operated on Curt was the father of Don's best friend. We didn't know this immediately, but the doctor had gone home the day before and told his son and Don how he had saved a young man's life.

Finally, on March 31<sup>st</sup>, he was allowed to go home. The pathology report on his spleen did not show any signs of cancer, so we were relieved. Since they weren't completely sure why his platelet count was so low, the doctor warned Curt that he should watch for petechiae. These are small pink or red spots all over the skin, which looks like a rash but is actually the capillaries bleeding. If he got these spots it would mean his platelet count was low and he could be hemorrhaging. If this should happen, we were to notify the doctor immediately.

## Chapter 2

On April 4<sup>th</sup>, the day after Easter, Curt went to get his staples removed from his incision and he received a clean bill of health. Curt joked with the doctor that he should tattoo the top of his scar to make it look like the tab of a zipper. He was more like his old self again although a little weak.

He spent the next several weeks recuperating and getting his strength back so he could start moving on with his life. He also bought a green 1967 Chevy Impala, which he decided he would restore. When Sheri saw him coming down the driveway in that car, she said she thought it was the ugliest car she had ever seen. She wasn't into old cars like her brother. On May 28<sup>th</sup> Curt turned nineteen, and we celebrated the fact that he had made it through a scary ordeal and had lived to see this birthday.

This happiness was short-lived. On June 3<sup>rd</sup> Curt called me at work to tell me that he had what looked like a rash all over his body. He remembered what the doctor told him, so he asked me what to do. I told him to call the doctor, which he did. The doctor told him to go to the hospital for a blood test to check his platelet count. The news was not good – his count was only 20,000. Normal is anywhere from 150,000 to 400,000. Anything lower than 50,000 is dangerous; and lower than 30,000 means you can hemorrhage at any time and die. The doctor told him to go home and take it easy. On Sunday they would do a re-check to see if there was any change.

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On June 5<sup>th</sup>, Carl and I would be married twenty-three years, so we went out to dinner on Saturday night. We really didn't expect anything bad to happen on Sunday, and planned to enjoy the day.

Curt went for his blood test first thing Sunday morning. The results came back showing his count did not rise as hoped. The doctor wanted him in the hospital to run some tests and give him platelets, so we brought Curt into Newton Memorial to be admitted again. He apologized for "ruining our anniversary". We didn't feel he had. We just wanted him to be well again.

Of course when we got there he asked if he could be placed in the pediatrics unit again, and since there were rooms available, the hospital agreed. The platelets arrived quite late in the day and they infused him shortly before visiting hours were over for the day. Suddenly, while we were sitting around talking, Curt started to get chills. We called the nurse who got him some extra blankets. It didn't seem to help as he soon started to shake all over. The nurse then brought some heated blankets from the operating room. This, along with Tylenol, seemed to help some, so we said our good-byes for the night and headed home, once again feeling strange about leaving our son in the hospital.

Quite early the next morning we got a call from Curt. Shortly after we left the night before, he had developed a high fever that they couldn't seem to break. So Curt was on a bed of ice and still had a fever. He didn't know what was happening and he was scared. When we got to the hospital he was still "on ice". We found out later that he had a reaction to the platelets. From then on, whenever he received blood products, he needed to be pre-medicated with Benadryl and Tylenol to avoid having this reaction.

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Our regular doctor was in charge of Curt's case at this point. He thought perhaps it was a virus causing the platelet drop and had a multitude of tests run. At the same time he called in a Hematologist/Oncologist to do a bone marrow test. Dr. Niranjana was a sweet Indian lady whom we liked instantly. She handled Curt well, even though he was worried about what was happening to him. The bone marrow test was a scary time for Curt, but they medicated him and he made it through the first of many on June 7<sup>th</sup>.

On Wednesday, Curt was released from the hospital. He would be going to his regular doctor twice a week to have his platelets checked while they tried to figure out what was wrong with him. They also put him on steroids since they help promote platelet growth.

Unfortunately, his platelets rose for a bit but then they dropped again. The doctor kept bumping up the dosage of steroids. Every time he went back to the doctor, he would be told that another test had come back negative for different viruses. They were trying everything, but couldn't seem to find the answer.

At the same time, Dr. Niranjana told us that she felt sure he had some form of blood virus or lymphoma; only she couldn't identify the type. Still, our local doctor held out some hope that it could be a virus such as Epstein-Barr.

Finally, around June 19<sup>th</sup>, Dr. Niranjana told us that she was sending the slides from his bone marrow test as well as Curt's spleen to the National Institutes of Health in Maryland to see if they could identify Curt's illness. At the same time, Curt's body was slowly losing the battle to keep producing platelets. He was on massive doses of steroids, and losing ground daily.

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By the 4<sup>th</sup> of July, Curt was a very sick young man. He had petechiae all over his body – even in his mouth and on his lips. He had a fever of 100°. His blood pressure was so low he was light-headed and couldn't stand. One of his toes started to bleed. He had no appetite and lost five pounds in one day. And still the doctors did not have an answer for us.

On July 12<sup>th</sup>, I received a call at work from Dr. Niranjana. She had received an answer from Dr. Jaffe at the National Institutes of Health. What Curt had was extremely rare and they had only seen one or two cases prior to Curt's. He had a Gamma-Delta T-Cell Lymphoma also called Peripheral Hepatosplenic T-Cell Lymphoma. The liver, spleen and lymph nodes are all involved. Basically, the cancer cells attack and destroy the platelets, and eventually a person would bleed to death. She also told me that only young men around Curt's age seem to contract this type of cancer. Since there had been so few cases, there was no known cure!

Dr. Niranjana wanted to see us in her office on the 14<sup>th</sup>. She would spend the two days until then trying to find a doctor or a hospital that would take Curt's case or at least help give some direction since we were dealing with a virtually unknown type of cancer. She had no answers on her own and knew he would die quickly if something weren't done. Standard chemotherapy just wouldn't cure him.

The first thing I did after I hung up with the doctor was sit at my desk and cry. I couldn't believe we could be losing our son. And I was scared to death of telling him what they found. After composing myself, the next thing I did was to call Carl to tell him the horrible news. I hated telling him over the phone, but I wanted him to have time

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to compose himself so we could both be there for Curt when we told him.

Then my boss came down to my office to see how I was. I suddenly realized that since Curt had turned 19 and was not in college he might not have health insurance coverage. I immediately called the insurance company and they said he was covered to the age of 23 whether he was in college or not – a rarity. I didn't believe them, so my boss called and verified that he did have coverage. I don't know what would have happened if he was no longer covered. Thankfully we didn't have to find out.

When we were all home, Carl and I told Curt that the test results had come back and that he had lymphoma. We didn't tell him that there was no cure or that it was rare. We wanted him to believe he had every chance to make it so he wouldn't give up hope. He reacted with shock and disbelief, but seemed to take it fairly well. Then he said he was going up to his friend Dan's house.

Dan lived up the road and was his best friend. Curt was also on the fire department with Dan's father. We found out later that Dan wasn't home when Curt got there, so Curt sat in his driveway waiting and was there crying when Dan came home.

We waded through the next two days, feeling our way alternately between anxiety, hope, fright, and determination; all the while hoping that this was all a big mistake, or that Dr. Niranjana would have some positive answers when we arrived at her office. We placed a lot of faith in her knowledge and skills – and also in God.

On July 14<sup>th</sup> we arrived at Dr. Niranjana's office full of hope and very scared. We thought she would be starting some type of chemotherapy that day, and that's

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what we had prepared Curt for. She checked him over, and explained that she still wasn't sure what protocol to use, since she couldn't find anyone with any better answers. If she started one form of chemotherapy and then came up with something better, we couldn't just change mid-stream. She didn't want to do anything that would hurt his chances. Also, Dr. Niranjana had called different hospitals around the country, and their replies were all the same. They all told her not to send him because either they had never heard of his type of cancer, or if they had seen a case they knew there was no hope. They told her he would die anyway, as there was no cure.

We had also been searching for answers, and had seen an article about Memorial Sloan Kettering in New York City. They had been ranked as the top cancer hospital in the country. We asked her if she had contacted them. She had but was still waiting for a reply. So while we were there she called them again. She got through and they told her that we would have to wait for an appointment in a couple of weeks. She explained that Curt didn't have a couple of weeks. Finally, she told us to bring him to Sloan Kettering on Tuesday the 19<sup>th</sup>. We only found out much later, that she argued all through the weekend to get them to take him immediately. They had finally agreed to take him on an emergency basis.

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