# Chapter 15

## *What are the Odds? Double Trouble… Again*

Life is interesting and unpredictable. In a relatively short period of time, the pendulum had swung from the deepest crevasses of hell, to the loftiest peaks of heaven, and we had experienced nearly every emotion in-between. Of course, I always hope for the best, but given our past history and experience with life, I'm always, subconsciously at least, waiting for the other shoe to drop.

I guess I was hoping we could rest for a while on this plateau, and maybe even settle into some good old fashion monotony. Jenny had moved back to the City and was doing great. Friends and social activities kept her busy all the time. I was finally feeling more comfortable with life too, and my personal health concerns seemed to be resolving themselves. Jeremy had taken up a new hobby... the drums. But this was more than just a hobby.

Jeremy was getting a little bored with just sitting around so much of the time, and his physical therapy was not only becoming tedious, but expensive. Dr. Madsen told us he knew a professional drummer who mentioned to him once that playing the drums was good physical therapy. It provided a workout for his entire body, plus it was relaxing and fun. He suggested that we might want to consider getting Jeremy involved playing drums. We were excited to think that maybe this would give Jeremy an emotional boost, as well as help him out physically. Dr. Madsen introduced Jeremy to his friend Steve, who agreed to help Jeremy get set up with drums, as well as give him lessons.

Steve's a great guy and a very talented musician. He was a Zildjian clinician, introducing the latest cymbals and newest techniques to other musicians, but he decided that life on the road was not the type of life that suited his family's needs. He retired from that and moved to our small town. He still wanted to be involved with music and so he took up private teaching. I was so happy when he volunteered to become Jeremy's teacher.

Jeremy was a good student, becoming so consumed with his drums, that he completed a two-year course in just six months. Steve was very pleased with his progress and so were we. He was finally getting more excited about life and becoming the Jeremy we used to know.

Lee was finally feeling more comfortable in his life, too. He got involved doing things he really enjoyed such as running in local races, including Marathons. It gave him something fun and healthy to do as well as providing a means of escape from many of the everyday stresses of life.

Once again, we had to sell our home to catch up on medical bills which were burying us. However, we were able to keep a little bit of the equity from the sale of our home to put down towards the purchase of an existing home located in an older part of town. This is the home we currently live in. We'd lost three homes to medical expenses and hoped we would finally be able to hold on to this one.

We settled in once again, and things seemed to be going as well as any of us could expect. Jeremy, however, started experiencing more pain and discomfort than usual, and we went to Dr. Madsen to seek his advice and expertise.

It had been twelve years since we'd had a check-up by the muscular dystrophy physicians, and Dr. Madsen recommended that we return there for a thorough exam. He felt like he'd done everything he knew how to do for us and said that maybe they could provide some new insight or ideas on how to better cope with this disease we shared. We did as he suggested.

During our drive to the City, Jeremy and I really had a really good conversation. Because we have so much in common, we can relate to each other in Ways that other people can't. We wish, of course, that we didn't have to share ***these*** things, but it has made us very close over the years.

The doctors looked at Jeremy's legs first since that was where he'd been noticing the most recent discomfort. The doctor looked at Jeremy's leg and said, "This isn't right. Your shin has moved clear over to the side of your leg. How are you walking?"

"Not very easily," said Jeremy, "I'm Walking, but it's pretty painful. I get a lot of leg cramps."

The doctors were baffled. They sent him to the orthopedic surgeons office for X-rays and more tests. I watched as people kept walking in and out of the office, and the longer he was in there, the more certain I became that something wasn't right. After a while, Jeremy came out of the office and sat down by my side. We'd been there quite a while. Finally, Jeremy leaned over to me and said, "If these doctors are getting paid by the hour, we're in trouble."

After a few minutes, the radiologist came out of the office, walked over to us and said, "Now Mom, what kind of a disease did they say you and your son have?"

Her manner irritated me. It bothers me when people come up to me and speak about Jeremy as if he isn't capable of speaking for himself. He was twenty-eight years old at the time! Granted, he looks quite young as a consequence of his conditions, but he's a man, and it makes me angry when people don't treat him like a man.

I looked up at the radiologist and said, " I'm really just here to support Jeremy. I'd really appreciate it if you'd ask him any questions you might have. He's twenty-eight years old and knows everything about his condition."

The radiologist redirected her question to Jeremy. Jeremy told her that at age six he'd been diagnosed with muscular dystrophy.

"Well," she replied, "muscular dystrophy couldn't have done this to you."

Now she had my attention.

"What on earth are you talking about? Couldn't do what to him?" I asked. "What is it that you think he might have?"

"You know I can't tell you that. You'll have to talk to your doctor to get that information." She said.

"Well, when will he tell us?" I asked a little impatiently.

"I'm not sure. You'll just have to go back to your room and wait till he gets there," she replied.

We were taken to a room and told to wait there for a few minutes. We waited for over an hour!

Jeremy was getting restless. "I can't wait here any longer. I need to go use the restroom." He said. He got up and left the room.

When he opened the door, there in the hallway were all these doctors, obviously discussing Jeremy's situation. He walked past them. There was a deafening silence as he walked by them.

After he returned, the doctors spoke with us. They said they'd never seen bones like Jeremy's before, ever! I wanted to see what they were talking about, so I asked to see the X-rays. They placed them up on the board. I've seen a lot of X-rays in my life, and I was absolutely shocked! In nearly thirty years in the medical field, I'd never seen anything like it either.

In some areas of his legs, the bones had grown so large that they seemed to take up the entire cavity of his leg, leaving no room at all for muscle or anything. Yet, in other areas his bones had become so thin, that it looked like they'd break if you just bumped him the wrong way.

The X-rays showed that his elbows were fused together. That would explain why he had to rotate his arms at his shoulders in order to make his hands lay flat. He couldn't turn his hands around like other people. Now I understood why he couldn't type any more.

As I looked at the X-rays, I was baffled, too! I thought it had to be bone cancer. What else could make his bones twist and turn like this?

I asked the doctors if they thought it was bone cancer, and their reply was that they weren't sure; however, they'd already taken the liberty of scheduling an appointment at a local cancer institute to have them take a look at him.

Jeremy got dressed. They handed him a card and said that he had an appointment to see them in two weeks.

We left the building and got into the car to drive back to my sister's house where we'd been staying. All of a sudden, Jeremy became very angry! He started to cry, and then he started to yell at me!

"This is all your fault!" he said. "You gave this to me! I can't handle this anymore. I'm done with it! I don't want the hurt anymore! I don't need another terminal illness! Isn't one enough?"

It felt as if someone had thrust a burning dagger into my heart. I felt like I had just betrayed my best friend, yet I knew that I would never betray my own son. Didn't he know that, too? My throat got tight and I began to cry.

"I'm so sorry... I would never have done this to you intentionally! I never knew I had anything wrong with me," I said.

"Don't you dare cry Mom. I just don't care anymore!" He yelled.

I continued to cry. The hurt was too much for me. He got quiet, and so did I... there was nothing more to say for now.

We arrived at my sister's house, and I was so grateful for her and her family. They were very supportive of both of us at this very traumatic time in our lives.

When we returned to home, Jeremy apologized for the way he'd spoken to me earlier. He realized I didn't ask for these problems any more than he did, and he knew that I didn't know about the muscular dystrophy until after he was born.

When I told Lee about it, he reacted pretty much like Jeremy.
He was angry, too. Then he remembered the accident Jeremy had been in. At that time the doctor mentioned that there was something "odd" about Jeremy's bones. He said at that time that Jeremy might have bone cancer, but the orthopedic doctor reassured him it wasn't, so Lee never gave it another thought. Neither Lee nor

Jeremy had bothered mentioning any of this to me. They said they wanted to spare me any unnecessary worry.

I went to Dr. Madsen again, and told him all that had happened. I asked him if he thought I should have X-rays taken of my long bones to see if I was also having similar things happen to me.

For years we'd been blaming all this misery on muscular dystrophy, and now it was being suggested that maybe that wasn't really what we had. I thought that if we did have something besides muscular dystrophy, that it would be valuable to find out what it was, in order to help Jeremy receive the correct diagnosis. He agreed that it would be a good thing to do.

During the next few weeks I had a series of X-rays taken of me. I asked the radiologist to send them to the Cancer Institute so they would be on hand when Jeremy and I went there for his appointment.

Every year, our town hosts the United Rock-Crawling and Off-Road Challenge for off-road enthusiasts. (UROC for short.) It provides an almost carnival-like atmosphere for a time, and we really enjoyed being a part of the fun.

It was during this time that all this possible bone cancer stuff was happening to us, and We needed a way to distance ourselves from the grim possibilities that lay ahead. It was Saturday morning and the last chance for Lee and the boys to get involved with the UROC festivities if they were going see them at all. I thought this might help us all get out of this depressing mental state we'd been in.

We love this sort of thing, so I asked Lee if he would take the boys out and let them see the events that were scheduled for that day. I wanted to go but felt like I needed some rest. He agreed it was a good idea. Lee left the house about eight in the morning and spent the entire day with the boys. They really had a good time.

Lee came home that evening and suggested that since I hadn't been out with them having fun that day, that he would take me to dinner that night. We went to one of our favorite restaurants. By the time we finished eating, it was dark. Ever since Lee had his cataract surgery it's been difficult for him to see very well in the dark, so I drove us home.

As we were driving, Lee noticed a truck off in the distance pulling a trailer and coming towards us. "Look," he said, "see that Jeep on the back of that trailer? That's one of the Jeeps we saw competing today."

We were just approaching a curve in the road and the truck and trailer were about to pass us going the opposite direction. I remember his headlights blinding me just for an instant. Suddenly, I heard this terribly loud explosion! The next thing I knew, I felt fluids running down my face and a burning sensation on my skin.

"Are you OK? Are you OK? ***What was that***?!" Lee yelled.

I managed to pull the car off to the side of the road, but by now I couldn't see a thing. My eyes were really hurting, as was my entire face. I realized that the warm fluid I was feeling trickling down my face was blood.

Lee fumbled through my purse and found my cell phone. He called 911. "Hang in there... help is coming," he said.

I still had no idea what had happened. He got out of the car and looked around for a minute, then got back into the car.

"Honey," he began, "you won't believe what just happened. One of the spare axels they were carrying must have come off the trailer and now it's sticking right through our front windshield!"

I shudder to think what might have happened if either we or the other truck had been going just a little bit faster. The axel had embedded itself into our windshield, stopping only inches from my face. It was a miracle that it stopped when it did. The truck driver apparently didn't even know he lost it. If he did, he never stopped. He just kept on driving down the road.

When the police arrived, they couldn't believe their eyes either. ***"What are the odds of this kind of thing happening?"*** asked one of the officers. Lee just grunted and said quietly, ***"Obviously this guy doesn't know who we are."***

The paramedics arrived, strapped me to a stretcher and put my neck in a brace. Then they hauled me off to the hospital. Lee wasn't allowed to come with me. He called Jenny and told her to come and pick him up and take him to the hospital. Lee called the other kids and told them what had happened. Soon all the kids were with us at the hospital.

"Now what?" asked Jeremy. "What else can possibly go wrong?" Jenny was hysterical. Before long she just kind of took over, as she began shouting instructions and information to the doctors.

"My mom's allergic to such and such. She can't be given any of that! Don't do this to her. You can't use that on her. She has a bad heart." Lee was trying to calm her down, but she was basically telling them my whole medical history.

They spent quite a while removing pieces of glass from my eyes and face. Chunks of glass had flown into my hair, down my blouse, and a bunch of glass was inside my clothing. My legs and pelvis seemed to be hurting now too.

The doctors thought that I ought to have some X-rays taken, just to make sure they hadn't missed anything.

They wheeled me down to radiology and put me on the table. Just then, the radiologist came in. She happened to be a good friend of mine and was surprised to see me.

"What on earth are you doing here?" she asked. I told her what had happened, and then she asked, "Did Dr. Madsen get hold of you with the results of the X-rays they took of you last week?"

I said he hadn't but that I'd given instructions to send them up to the Cancer Institute when they came in.

"Well," she said, "you need to call Dr. Madsen first thing Monday morning and have a talk with him."

The doctors wanted to keep me overnight for observation, but I refused. I'd had enough hospitals for this week and just wanted to go home and rest in my own bed. So, I signed a release form so they'd let me go home.

Monday morning, I called Dr. Madsen's office. He told me that there appeared to be something wrong with my hips. It looked to him like it could be bone cancer.

"Oh my gosh," I said. "What are the chances that I could have developed bone cancer the same time as Jeremy?"

We had both been diagnosed with muscular dystrophy when Jeremy was six years old and now here we are both being suspected of having developed some sort of bone cancer, as well.

Dr. Madsen called up to the Cancer Institute and asked them if they would see me at the same time they saw Jeremy. He explained the situation to them and said that he thought that I might have the same condition as Jeremy. He suggested it might be more beneficial to have both of us there to examine at the same time. The doctors agreed.

Lee decided that this time he was coming up with us to keep an eye on us in case there was more bad news. He wasn't sure how we might respond if there was bad news, but if there was, he didn't want us to be alone.

Lee was frustrated and angry with all the things he saw happening to our family, and he felt completely helpless. He knew there was nothing he could do about any of this, and that was hard for him to deal with.

We arrived at the institute and Jeremy and I were both admitted. There were several doctors who kept coming in and examining us. They would check one thing, consult with each other, leave the room, and then some new doctors would come in. This went on for a while, until about six doctors came into the room all at the same time.

One of the doctors said, "We don't think its bone cancer... but after looking at your charts and analyzing your X-rays and other information we have on you, I'll tell you what I think you might have. I learned about a very rare bone disease while I was attending a medical conference in Baltimore, and I believe you may have that disease. There's only a slim chance you have it, because it's very, very, very, very rare. To give you an idea of just how rare it is, there are only about three hundred people in the entire world that are known to have had this disease in the past 45 years."

Lee's mouth dropped. He couldn't believe what he was hearing. Jeremy spoke up and asked, "Well, what is it called? What is it exactly that you think we've got?"

The doctor thought for a moment and then said, "Well Jeremy, the technical name for it is Camuarti-Engelmamis / diaphyseal dysplasia. Possible long-term effects include loss of sight and hearing. Your bones will continue to grow and become deformed... your hips will probably have to be replaced. Your elbows and shoulders will probably all have to be operated on eventually because they will fuse together. When the bones start growing way out of control, it will probably affect every organ in your body. It could even affect your heart so that it won't function properly. "

When I heard that, I immediately thought of my own recent heart problems. I'd already been through three heart surgeries and wondered if maybe this could have something to do with it.

The doctor continued on with a whole list of nightmarish possibilities that could happen to us. I took a deep breath and closed my eyes. It was all feeling surreal and frankly impossible to comprehend. Was this all just some horrible nightmare that I needed to wake up from?

Just when I was sure there couldn't be anything worse than the things he'd already told us, he said; "That's not all. Eventually your skull will start growing into itself and squeeze your brain. Your jaws will fuse shut, and you will go deaf and blind. There are some other things that could happen too. We have no idea how to treat this. All I know is the information that I've found on the subject on the internet."

Then, without even skipping a beat and with almost the same excitement you'd expect of someone who just won the lottery, he said, "But this is all very exciting! You're the only two people in all of our State who have this rare illness. I can't wait to get you into my classes to introduce you to my students. I've heard there's a medication that may help. It's an IV medication that you can take. We'll have to put a pic line in, and then we'll give you continuous medications throughout the month and..."

Just then Lee interrupted. "Whoa... just a minute. Can I ask you a question? Our insurance won't cover this at your facility, because you're not on the approved list of providers for our Insurance. Can this be done at an approved Hospital? We have pretty good insurance, but we've been financially devastated by medical bills in the past, and there's no way we can even consider doing something like this any place except for those places approved by our insurance. The doctor looked at him and said, "No, that Hospital doesn't have the capability to treat this type of illness, nor the expertise. I don't think it would be a good idea to try to go over there." "Well, what can we do?" asked Lee. "We really don't have any way to pay for this ourselves."

The whole demeanor of the group seemed to change. Everyone got very quiet, until one lady, an assistant spoke up and said, "Well I'm sure that we could talk to a financial counselor and see if there's something that we could do for these people."

"Yes, that's a good idea," said the doctor. “Why don't we go out and see if there's something that can be done for them."

They all left the room; leaving us sitting there to ponder just what it was that had taken place. They weren't gone five minutes, when one of the doctors returned and said, "Here's a prescription for your IV. Here's the name so you can look it up on the web, and uh... well... you'll probably know more about this disease than I ever will. I wish I could be more helpful, but I'm really, really busy right now. I'd like to help more, but I'm so busy with this cancer tumor research I'm doing right now, and I really don't have time to learn about a new condition that only affects two people."

We could hardly believe what we were hearing. Don't get me wrong, I was glad that this doctor was doing cancer research and trying to help other people. Our family's been greatly affected by cancer! I lost a sister-in-law, several aunts and cousins, to cancer and I am ***very*** grateful that he's looking for a way to help, but with this recent diagnosis, we felt totally overwhelmed. It's sort of like getting dropped off in the middle of the desert with no supplies, no maps, and having someone say... OK... have a nice trip! And then simply disappear. That's what it felt like.

Then it hit me; it's all about the money! I'll bet that the reason they're not interested in helping us is simply because there's no money in it! Just moments before, he'd been so excited about researching this disease, and sharing us with his classes and helping us out in so many ways. But as soon as he found out that we couldn't pay for all this attention, he dropped us like a hot potato.

As he escorted us out the door and down the hall, I turned to him and asked, "What about this prescription? Where do we get it?"

Just then his assistant turned to him and asked, "Well, aren't we going to do the pic line here to get them started?"

"Oh no, that's not necessary," said the doctor. "I'm sure they can find someone in their town who can help them with that."

I thought to myself, "Why does this guy think we're here? Our little hospital in our town doesn't have the ability to take care of us there... that's why we came here!"

His assistant obviously felt bad for the way we were being brushed aside. She even apologized to me, saying that she really felt bad for the way we'd been treated, but of course there was nothing she could do.

As we walked out the door of the institute, Jeremy turned to Lee and me and said, "Here... you have a terminal illness... only three hundred people in the whole world have it. You're gonna lose your sight, your hearing, your brain's gonna get squeezed and your organs are gonna shut down, but here... go figure it out on the Internet!" Jeremy couldn't believe what had just happened. He felt anger and frustration and I couldn't blame him.

We went home and told the other kids what had happened. Jenny took it very hard. She started crying again and wanted to be right by me all the time. She was already worried about me because of some foot surgery that was scheduled for me the following week.

This was all becoming too complicated to deal with. Here we'd gone through life telling everyone we had Muscular Dystrophy, and now we weren't sure. We'd worked for years raising money to find a cure for MD, hoping it could help us, too, and now it looked like no one could ever help us.

After thinking about it for a while, I realized that we weren't even sure we had this. . .Cama. . .Camarati. . .whatever it was. But how could we find out for sure?

I could tell that Lee was finally nearing the end of his rope. He'd just about had enough of life and the hands he and his family kept being dealt.

This new condition, with its exotic sounding name, was taking a toll on my entire family, and I didn't like what I was seeing. I didn't like the fact that Lee was losing his sense of humor again and getting more and more discouraged every day. This wasn't like Lee. I decided that the best way to fight this demon was to get educated about it. At least by understanding it better, I felt like I could better cope with it and all its diabolical effects.

So, I made a commitment to find out everything I could about it. I would get better educated about it than any of the doctors at the cancer institute. I couldn't just sit around mired in ignorance. I found the note that the doctor had given me with the name on it that might hold the key to better understanding what it was we were up against.

I got myself a pencil and paper and a large glass of water. I turned on the computer and waited for it to boot up. I was determined to sit there for as long as it took to find some answers. I wanted to find some information that might provide at least a glimmer of hope for Jeremy and me. After all, at this point, hope was all we had.