Chapter 16

Help Us – Help Them – Help You

I went to the internet and typed in the name of the disease they said Jeremy and I had. "DIAPHYSEAL DYSPLASIA"… then I hit "Enter". The search engine popped up a number of matches, and I noticed that most of them said... "Diaphyseal Dysplasia... Camurati-Engelmann."

The next thing I noticed was that many of the references and articles mentioned a particular doctor who was apparently the leading authority in the entire country on the subject. His name is Dr. Victor McKusick, and he'd studied this particular illness for over forty-five years. He was linked with the Johns Hopkins University Medical Center, so I decided that he was the person I wanted to talk to.

I went to the Johns Hopkins Medical Center Website, and after browsing through all the information that was there, I decided to call the Medical Center and speak directly with Dr. McKusick.

I called the main offices and was informed that Dr. McKusick was no longer practicing. I explained that I really needed to speak with him about our situation and asked if she could give me a number where I might reach him. She told me she couldn't give out that information, but if I wanted to see some of his writings, or study up on the subject, I could go to the Johns Hopkins University website, and maybe that would help me.

I went to the website again and looked up staff and faculty information. It came up on the screen, and I looked up Dr. McKusick's name. I hit the hyperlink that I thought would bring me to his web page. The computer brought up a lot of additional information, but none of the stuff I wanted to access would come up without first entering a password. The prompt read, "Faculty Information - Password Please."

I sat there for a minute thinking to myself.... password... password... what could their password possibly be? I had only pondered this question for a moment when a word popped right into my head. I typed in the word that came to my mind, hit "enter," and Click! I was in! There on my computer screen was all the information on all the faculty and staff of the whole University. I felt a bit like a hacker. I wasn't sure if anyone would want me to be in there, so I just hurried and wrote down Dr. McKusick's phone numbers that were listed, and then shut down my computer.

I called the first number listed and got his secretary. I told her of our situation and asked if they could help us. She told me who I needed to contact and said that she would transfer me to them. She assured me that I would be very well taken care of.

When I finally got connected to the right people, it was amazing. I'd been trying to talk to doctors and other professionals in the medical community about what Jeremy and I had, but no one seemed to know what I was talking about.

Now I was finally speaking with a person who obviously knew what I was talking about, who had answers that no one had ever been able to give to me. One of the first things she said to me was, "Now you're aware that this is a very, very, very, very rare disease, aren't you?" I told her I was more than aware of that fact. I had been told many times just how rare it was. She told me that Dr. McKusick had studied this disease at a clinic in Belgium. That's where the majority of people who had this disease were being treated.

Because this was such a rare disease, and because both Jeremy and I had been tentatively diagnosed with it, she said that they would like to examine us to determine whether or not we actually had it. We were told that we would also be able to receive short term care at their facility. Hopefully they could find a doctor closer to home to take care of us for the long term. She told me what information they needed me to bring when Jeremy and I came for our appointment, and what they expected to accomplish during our first visit.

I was so excited! Maybe, finally, we could receive some help with some of the problems we were facing in our lives.

I told her about Jenny's problems and asked if she thought there might be a connection between her problems and this disease. She told me to write down all my questions and concerns and be sure to bring them along with me when we came.

I couldn't wait to tell Lee that I'd finally spoken to someone who knew about this disease, and that I'd made an appointment for us to meet with them. I told Jeremy what I'd done, and he was very excited.

When Lee arrived home that night, I told him everything that happened. He didn't respond at all the way I thought he would. I could sense that there was something wrong. I felt like he was angry with me, or unhappy that I'd made the call to Johns Hopkins. I looked at him and asked, "What's wrong Lee?"

He looked at me and said, ***"I can't afford to lose one more home. I'm tired. I can't go through this anymore. I'm getting old, and I just can't stand the thoughts of having to build any more houses. I can't do it again!"***

I understood his concerns, they were mine as well. We'd already lost three beautiful homes to medical bills. I tried to convince him that it wouldn't happen again… *"We won't have to lose our home,"* I said. *"We have insurance now and they'll pay for it."*

"Fine," he said "Give ‘em a call and see what they'll do."

I called our insurance company, and they told me they'd never even heard of Camurati-Englemann's disease and that they'd have to investigate it further and get back with me.

Well, they didn't get back with me, so I called them back. They informed me that because we were ***choosing*** to go out of their network of accepted doctors, they would only be able to pay fifty percent of the expense. Furthermore, we would be required to pay a hundred-dollar deductible and a two-hundred-dollar penalty *for going outside of the network*.

I was devastated! It was going to cost five hundred dollars for each of us, just to go back there and have a consultation with the doctors. That didn't include any testing or medication or anything. That was just for the initial consultation. This would leave the insurance company with very little to pick up.

I was angry. We got insurance through Lee's work, believing that we would finally get good coverage, and now they were looking for every excuse they could think of so they wouldn't have to pay out! We'd closed down Lee's company so he could go to work for a large company with *supposedly* great insurance benefits. Now, we weren't getting that much more coverage with this big group plan than we had been getting with our small business plan. And Lee was earning a whole lot less.

Why couldn't we just have normal diseases like everybody else? Why do we always seem to get the really odd things that our insurance won't cover?

My heart operation wasn't covered, because the procedure wasn't yet approved by the FDA when I had it. That cost us our home. Now, because we had a disease that nobody ever heard of, and since only a few doctors in the entire country know anything about it, we were penalized again! Nobody wanted to pay for my heart surgery, nobody would pay for Jason's accident, nobody would pay for my neck surgery, and now we found ourselves in the same mess again.

The insurance company would only pay two hundred dollars out of a thousand, and we just didn't have any way we could come up with the money to pay for the rest of it. And that was just the tip of the ice-berg. We would have to come up with the air-fare, hotel, food, the rental car to get back and forth to the clinic. I knew this would overwhelm Lee when I told him, but I had to tell him.

I was right. When I told him what I'd found out, I could see the look in his eyes. I knew that this was just too much to ask of him. I said, "Just forget it... we won't go back East." I couldn't ask him to throw it all away again.

I went to Jeremy and said, "Jer, we can't go. I can't ask your dad to go through all this again. We won't be able to go back to Johns Hopkins... at least not now."

Jeremy looked at me and said, "Mom, I need to know what's happening to me! I need answers and these people are the only people that can help me... the only people who can help us! What if something else happens? What if my body starts changing and doctors around here can't help me. I need to know what I can do and how to deal with it."

I felt like I was really being torn apart now. This dilemma seemed to have no acceptable solution! I asked Jeremy to come with me for a minute.

I walked over to a large mirror and stood next to him facing the mirror.

"Look at us Jeremy, We're the same people we were before we found out that we had Camurati-Englemanns. There's no difference in us now. We've always had this terminal illness, and that's not going to change."

I know that one of the main reasons Jeremy was feeling so frustrated about all this was because of how involved I had gotten him in the process of researching the disease. As we searched out information about this new disease, we often ran across medical writings that said that people with Camurati-Englemann's are often misdiagnosed as having muscular dystrophy.

Another article said that this was a very rare form of muscular dystrophy. Still another said that it wasn't muscular dystrophy at all but was instead a rare bone disease. Jeremy just wanted to find out the truth about himself.

I could see the hurt and discouragement in his eyes... now I was really between a rock and a hard place. Two of the men I loved most in life were about to be impacted in serious ways. I didn't know how to satisfy one without causing the other agony and pain.

I decided that since the "experts" couldn't even agree on exactly what it was that we had, and since we weren't even sure that there was any medication that could help us, that we should just continue on the way we were. We didn't know whether or not we could even be helped. But we did know that whatever happened, if we went to the doctors again, it would just be too much for us to handle financially. The person who would bear the brunt of that would be Lee. I couldn't do that to him… not again.

This was a really hard time for all of us. The thought just kept haunting me, "What if someone back East ***can*** help us? What if they could find a cure? By not going, was I sealing the fate of my own son?" It ate at me constantly.

For some unknown reason, my feet began to hurt. X-rays revealed that several of the bones in my feet had hairline fractures, and no one could figure out why. My doctor told me that he would need to operate on them and insert some pins so they could heal. I decided to just focus on that for the time being. I told Lee that I would table the idea of going back to Johns Hopkins for now. If some miracle happened, then we would look at it again, but I wasn't going to hold my breath. Still, I couldn't help wondering. . .what if?

Well, I had my foot operated on. They removed some growths that came from the core of my bone. They had to break a bone on the side of my foot, realign it and pin it in place. The hope was that this operation would eventually alleviate some of the pain that I'd been experiencing when I walked.

The operation seemed to be successful. I would need to be in a wheelchair for about six weeks, and I couldn't put any pressure on my foot during my recuperation period and they were concerned about my hip having pressure on it as well.

About five weeks into the recovery process, doctors discovered that I had developed a lot of infection in the wound, so it wasn't healing properly. They put me on strong antibiotics, but soon decided that the only way to fix the problem was to open me up again and clean it out. That's what they did.

They found that a screw had worked itself loose and created some problems in my foot. So, they decided to go in again, scrape it out good, and start over. Because of all the infection, they couldn't remove the pins at this time.

I was still secretly holding out hope that somehow, we would be able to go to Johns Hopkins University and visit with the doctors there. I wanted to be able to walk around there when and if it ever happened.

After some time, my foot finally did heal, and I went back to the hospital for a third operation to remove the screw and pins. This time the bones seemed to stay put. I had to stay off my foot for another week, making a total of twelve weeks I'd had to stay in a wheel chair. At the end of this last week, they put on a special boot, and I started walking on my own again.

Lee had been watching Jeremy and me for the past few months. He saw our suffering, and knew our desires to go to Johns Hopkins, even though we never spoke of it to him. He'd done a lot of soul-searching and pondering about us. As we lay there in bed one night, he said to me, ***"I can't take it any longer. I can't bear the thought of losing you or Jeremy. You're my two best friends in the whole world and I don't know what I'd do if you were taken from me."***

I could see that this whole thing had taken a toll on Lee spiritually. He seemed to have given up all hope, and worse than that, he seemed to be ***losing*** his faith. I think that all the anger and the frustration had taken away his desire to do the things that he knew he should be doing. I needed help.

I decided to talk to our church leader, Grant, and see if he had any counsel for me. I went in to see him, and as I started to tell him of our predicament I just fell apart. I started to cry and told him of my concerns for Lee, Jeremy, and all the rest of my family. I told him that I could deal with ***my*** personal problems... I could deal with ***my*** pain. But to see how this was affecting the rest of my family was more than I could bear. I told him how Jenny had lost that youthful exuberance through constant worry for her mother and brother. How she'd left a really good job, because mentally and emotionally she just couldn't stand to be away from the family with all the turmoil that was going on in our lives. I told him how Lee had lost that twinkle in his eye... how humor had given way to cynicism and his faith had been replaced by fear.

I went to my church leader, hoping to hear some words of wisdom or comfort that might give me strength to face one more day. I hoped for some counsel that would help me understand better how to assist my family with their individual struggles.

After I finished "bearing my soul" to him, he looked across the desk at me and said, "Linda, I've been thinking about you and your family a lot these past few weeks. I've been praying a lot, too, to know just what I could do to help you out."

"I feel you ought to go back to Johns Hopkins. I believe that it will bring comfort and peace to your life when you do, and I promise you that a way will be opened for you to go."

With Grants blessing, and believing that he was inspired, we made an appointment to go back to Johns Hopkins. We weren't sure how it would all come about, but we had faith that it would.

I was happy for Jeremy and hoped that maybe now he could find some of the answers to the questions he had. I understood totally what he was feeling.

As a young girl, I too wanted answers. All I got was criticism and accusations that I was making it up, or that it was all in my head. I wanted better for him. I hoped that Lee would be excited about the advice I got from Grant, but it wasn't that easy for him. ***He still believed that this was just the beginning of another bad dream... one that would end just like all the others had.*** He couldn't seem to shake off the depression and the discouragement like he'd been able to do so many times before.

He was a marathon runner and loved running and getting out in nature and enjoying life. Now, he'd quit running, and he'd just come home from work and sit around... he didn't even enjoy watching television or movies any more. It seemed like he was giving up on life. He used to look forward to going to work every day, but now it became a chore he resented.

It seems like whenever I've been discouraged or felt overwhelmed in the past, I'd get a phone call from my good friend Janice, and she'd say, "OK, tell me what's happening in your life," or "'How's things going with you guys?" Then I'd tell her about all the things that were happening, and she'd know just the right things to say to cheer me up. She always seemed to know when I needed someone to talk to. Her sympathy and advice were always a comfort to me. Her husband Lester seems to have that same type of relationship with Lee. When they get together, they joke and laugh, and things seem to smooth themselves out. After I'd finished praying, the phone rang. It was Janice.

"Hi Linda... how's things going down South?"

I told her about all the crazy things that were happening in our lives, about the new disease we'd been diagnosed with, the axel accident and the operations and then I told her how worried I was for Lee. How he just wasn't bouncing back from this round of problems like he'd done in the past. I told her that I was at the end of my rope and didn't know what to do.

She said, "Don't you worry any more... Lester and I are coming down to see you guys this weekend. We'll get out and have a good time. Maybe we can help cheer Lee up a bit too."

I was so excited to have them coming down to see us. I told Lee that they were coming down and wanted to do some fun things with us. I could tell he was happy at the prospect of seeing them again. Lee has always liked being around Lester because he's always felt that his friendship was genuine, and that he's never judged him unfairly.

And I love being around Janice. Whenever I'm around her, she seems to light up my life. Sometimes we'd go for years, without seeing each other, but the moment we meet again, it's as if we were never apart. I think that's the mark of a true friend.

They arrived in town and came to our house. They said they wanted to take us out to dinner and have some fun that night. So, we did just that.

During dinner Lester asked, "Have you ever wondered why so many crazy things have happened to your family?"

"Who knows?" said Lee, "But I hear people say some pretty dumb things once in a while. Things like "Gee, the Lord must love you," or "Golly, you're such a special person to be able to handle all those trials." Hey, what choice do we have? It's not like we asked for this stuff. All we can do is to try and deal with it the best way we can."

One of the things that really bothered Lee recently, was a conversation he was having with some friends and someone asked him how they found out that Jeremy and I had Camurati-Englemanns? I explained that Jeremy and I had been in two separate accidents, each requiring X-rays, and that's what had initially caused them to notice something strange happening to us. Lee's friend looked at Lee, and said, "Wow, I guess it was really a blessing for you guys to get in those accidents so they could find out what you got!"

This bothered Lee. How could anyone think we should feel blessed when we'd nearly gotten killed? I'm sorry, but we just don't feel all that blessed when tragedy strikes. Here we were, staring at the possibility of losing everything ***again***. We were worried about what this new disease would do to us, and how we could possibly deal with it, and people were telling us how blessed we were! "I'm sorry," said Lee, "but at times like this, it's really hard for me to imagine that these problems are really blessings!"

We spoke for a while, and Lee voiced some of his frustrations. After some serious talking and some venting, Lee and Lester started joking around. The mood lightened up and we ended up having a great evening.

When we went home, we sat out on the front porch, and just talked. It was nice to just sit and talk. The night air was refreshing.

Lester asked me if I'd ever considered writing a book about my life's story, and all the experiences our family had gone through. I told him that I had thought about it... mainly because so many people told me I should. Whenever Jeremy and I would speak in church or at civic gatherings, or sing songs together, we knew that people were touched by our stories and experiences, because they'd come up to us afterwards and tell us that we ought to write all these experiences down in a book. But I wondered if anyone would buy it, or if anyone would even believe that all this could really happen to one family?

I've sat down on many occasions and tried to put my thoughts down on paper, but it never really felt right. I worried that it might come off looking like I was boasting about the things we'd been through, and that's not the intent.

Then Lester offered to help write my story, and I immediately thought... why not? Who better to assist me than someone who's known me almost all my life? Here's someone who knew me all the time I was growing up and has seen the different stages of my life. He'd been a good friend, and I knew that he would represent the facts honestly. I wanted to talk to Lee about it first.

Lee and I discussed the book idea, and the fact that I would have to go up North for quite some time. I sensed that he had mixed emotions. He understood that I needed something to hope for and believe in. It was very hard for me to just sit and do nothing while this cloud of uncertainty hung over us. We were both feeling emotionally smothered, with little hope for the future. I felt like this book might at least give Jeremy some hope and purpose in his life. It might even be able to help us financially if enough people find it interesting. Lee and I have never been the type of people to ask for help, but we reasoned that this book just might be able to help us out, as well as provide some help to others. I knew it would be hard for Lee to have me away from home, especially with him being so depressed. We decided to sleep on it.

The next day, we went to the Mountains and spent the entire day just having fun together. As the day progressed, I could see that sparkle begin to return to Lee's eyes. I saw him start to laugh and joke around again. Lee was once again becoming the Lee I knew and loved. By the end of the day, Lee agreed that we should write the book.

Janice and Lester felt I should record the experiences of my life on tape. I believed that this could best be accomplished if I went to their home and live there while I did it.

I knew this would take some time, and that I'd miss my family, but I knew I had to do it.

Before Lester and Janice returned home it was agreed… Lester would help me write my story, but first Lee, Jeremy and I would prepare to go to Johns Hopkins.