

Chapter 17

It's Time to Fly!

The day approached for us to go to Johns-Hopkins Medical Center. I still had no idea how we were going to finance the trip. I began to wonder if I'd allowed my emotional desires to override common sense and logic. Had I really done the right thing? What if this latest diagnosis wasn't really what we had? After all, I'd been told over the years that my problems were probably a result of polio, or rheumatic fever, and then muscular dystrophy. The doctors at the cancer institute were really just guessing. They admitted that they had no expertise in this area.

So many people were encouraging us to go to Johns-Hopkins that I felt it probably was the right thing to do. I honestly believed that the doctors there would be able to answer many of the questions we had, and that in itself would be worth the trip.

Then I would start to think about our insurance, and how they'd only pay two hundred dollars out of every thousand. Where were we going to come up with the rest of the money? Just thinking about it was overwhelming. I started to feel frightened.

About a week before we were scheduled to leave for Baltimore, our church leader, Grant, came over to visit. He handed me an envelope. I opened it up, and I couldn't believe my eyes! Inside the envelope were airline tickets to Baltimore, hotel reservations, rental car reservations, and cash for food, parking, and whatever else we would need on our trip. It was another miracle.

Then, just three days before we were to leave, my sister-in-law came to visit. She and the rest of the family had opened up a bank account at one of the local banks, and invited anyone who wanted to, to put money into the account to help pay the medical costs that this trip would create. We were so touched.

Of course, it wouldn't pay for *all* the medical expenses incurred on the trip. We knew that. Neither one of us have any wealthy relatives in our families, so for them to continue to give to us, when they needed it so much themselves, was a true sacrifice on their part. We were so grateful for the outpouring of love, compassion and concern that so many people had shown towards us. It was something we'll never forget.

The big day finally arrived, and we flew to Baltimore. We had dozens of questions, mixed emotions, and even a little fear, as we flew out that day.

The trip took many hours. We left early in the morning, but with layovers and plane changes, we didn't arrive in Baltimore till after 2:00 AM the following morning.

When we finally arrived, Jeremy and I were beat. Our bodies really hurt because of all the sitting we'd done. Sometimes just sitting is one of the hardest things for us to do.

Once we arrived, however, our spirits rose simply because the people there were so nice to us. The hotel people were wonderful, and they had great rooms with soft beds! I couldn't believe we got a hotel with soft beds! Just being able to sleep in a comfortable bed was very helpful.

The next morning, we woke up and got ready for our first day at the hospital. Jeremy was quite nervous about what the doctors might say, and even more nervous about what they were going to do.

The traffic was crazy. It was a real challenge for us just to negotiate the roads to the hospital. It wasn't like our little town. And the parking was awful! Between the hotel and the hospital, it cost us anywhere from thirty to forty dollars a day, just to park.

When we first arrived at the hospital, I believe the doctors may have been a bit skeptical that we really had Camurati-Englemann disease. After all, there have only been about 300 documented cases of the disease in the past forty five years in the entire world! (or so we were told...) So, to have two people just pop in out of the blue and say, "Hi, we think we have Camurati-Englemann disease!" Well, it probably didn't seem very likely.

They took us in however, talked to us, then ran some tests and took some X-rays. Once the X-rays came back they totally changed their demeanor towards us. All of the sudden, doctor after doctor started coming in, all wanting to see us and shake our hands. They wanted to talk to us, and then examine us. It was just amazing, and such a change from the last hospital we'd been to.

The doctors were very helpful and seemed genuinely excited to see us. They'd say things like, "Welcome! Come in! Let's see what we can do for you. Yes, this is a legitimate disease, and we are giving you a clinical diagnosis that you indeed *do have* Caumrati-Englemann's disease."

It was almost funny. Doctors would cut short their lunch hour just to come in and speak with us. They'd come to visit in between surgeries or when they had breaks. Anytime they could, they made an effort be with us. I think they liked the idea of actually meeting real live people with this rare disease.

These people were awesome! Even Lee was impressed with how nice we were being treated. When they'd take us to do more X-rays, the doctors would accompany us and talk with us along the way. When they'd take us for other tests, they would stay right with us. They made us feel more like we were celebrities than patients. When we went for blood tests, or tissue samples, or biopsies, they never sent us with secretaries or nurses or other staff members. It was the **doctors** themselves who took us from one department to the other. We felt very honored.

Once the news spread that we were there, doctor after doctor made requests for us to come and see them and talk with them. They would even personally escort us to the next physician's office, so that we could fit in all the visits that were being requested. For five days doctors kept us busy with tests, lab work, exams, interviews, and on and on. We were busy from seven in the morning until five at night. It was hard work for Jeremy and me.

Many of the tests were painful, especially for Jeremy. They just kept on requesting more blood and more biopsies. Many of the things we did were not pleasant, but we knew they were all necessary.

I was so proud of Jeremy. They had to poke him in three different places in order to get the twelve vials of blood they needed. Then they did a blood-gasses test, where they had to go down deep into one of the arteries of his tiny wrist to get a sample of his blood to check its oxygen content. This was an extremely painful test, but he just sat there and held Lee's hand and took it like a trooper. I'm not sure who was hurting the most, Jeremy or Lee. It's hard to be a parent and watch your child go through terrible pain over and over again. Yet he felt like he wanted to do all that he could do to help find a cure for this disease so others wouldn't have to go through the things that we've gone through over the years.

One of the doctors at the Cancer Center in our State had been skeptical that we even had muscular dystrophy at all. But after being examined by the neuromuscular doctor at the Johns-Hopkins Hospital, he assured us that we did indeed have muscular dystrophy as well. And now we have the dubious distinction of each having two terminal illnesses concurrently.

The doctors informed us that because of how rare this disease is, and the fact that there are basically no people to examine here in the U.S., all that's currently being done at Johns-Hopkins for this disease are gene studies. For that reason, all the blood samples and tissue samples they took from us were sent to Germany for testing, where they've been more closely involved with people who are affected by this disease.

At the end of our visit, we met with a team of physicians who sat down with Lee, Jeremy and me. Once again, our diagnosis of Camurati-Englemanns was confirmed. One of the counselors said that there were only twenty families in the entire world that were currently known to be affected by this disease. Eighteen of those families were in Europe, and two were here in the United States. Jeremy and I were two of only 3 people in United States known to be diagnosed. Lee asked how many patients they had personally treated in their hospital. Their response was, "Only two," as they pointed at Jeremy and me.

I was told that I was the oldest living person in the United States to have the disease. (I wasn't sure how I should feel about that). The doctors wanted us to stay longer and have more tests and interviews, but it was just too hard on us. Besides, we were getting worried what all this attention and testing was going to cost us! We decided we'd better go home.

As we left Johns Hopkins, one of the doctors pulled me aside and said, "Here is my home phone number, my pager, and my cell phone number. If you ever have any questions or problems, or if you encounter doctors who don't understand this disease because of the rarity of it, just call me, anytime, and I'll be happy to speak with them and help in any way I can."

Another doctor shook Lee's hand, gave me and Jeremy a hug and said, "You'll never know how much you've affected me. I'm so grateful to have gotten to know you and your family."

All the people at the Johns-Hopkins Hospital were so gracious. We will always be grateful for their help and concern.

Our church leader was right. We did find a peace through our visit to Johns Hopkins. That peace, I believe, is in finally knowing what it is that we're up against. Knowing that this is a real disease, one with a name that we now understand a little better, has given us hope for the future. It was also good to know that there are people who are trying their best to help find a cure for it.

In a referral letter we received from Dr. Ronald Cohn, of the Johns-Hopkins Hospital, he wrote, "They will need to acquire a team of physicians who can oversee their management to insure the best outcomes. They will need a neurologist, especially one who specializes in muscle disorders, an orthopedist, a pulmonologist, a cardiologist, an ophthalmologist and an ENT (ear, nose and throat) physician. Because of the rarity of this condition, we cannot as physicians know what it is like to live with this condition."

The downside to all of this of course, is the hospital bills that will continue to pile up. We were told that one of the worst things that people can do who have this disease is to stress. Stress creates toxins that cause this particular gene to malfunction even more, causing problems for the body and accelerating the effects of the disease. They said we would need to modify our diets, and stay on a prescribed diet religiously, in order to help us stay as healthy as possible.

The bottom line here is, that they gave us some great council on how to cope with our condition, and instruction on the types of doctors that we will need in order to live as long as is possible. But all this takes money, and that's one thing we don't have.

I'd love to be able to implement the type of therapy program they recommend. But again, all this costs money. ***Worrying about how we will be able to get the money, causes stress which accelerates the symptoms of the disease. It's a vicious cycle.***

I know they will help us all they can, but I also know that currently there are no cures for the diseases we have. In spite of all that, I will go forward every day, encouraging Jeremy and the rest of our family to simply live life one day at a time, the best we know how.

I know that the most important thing I can do is to continue to have faith in Heavenly Father, and trust that He will take me home when He determines it's time for me to come home. I'm sure that He is very much aware of everything we are going through. I also know that as we've gone through these trials, angels have been walking at our sides, supporting us.

That's why we're able to find the strength to go forward and live each day of our lives. I know that there is another place where we'll go someday... a place where there will never again be pain or suffering. A place where we will finally and forever find the peace that we all seek for in this life.

I only pray that I'll have the strength to go forward now; today, and remain as positive and happy as I can possibly can, so that I can help those around me find happiness, too.

I'll continue to work hand in hand with doctors from our University Hospital, as well as the doctors from Johns-Hopkins. These are the only places we know of where there are doctors who can help us with our problems. Again, they're "out of network" hospitals and doctors, and our insurance company will only pay for a very small portion of the expenses.

Nobody ever said life would be easy, and I know that if I hold on to my faith, that things will turn out the way that they're supposed to. We'll continue forward and do the best we can. I Want others to know, that even though sometimes life seems unfair, that there is a plan for happiness that God has for each of us, but we must realize that it's a long-range plan.

People often ask how I can go on, knowing that I have these terminal illnesses. My answer is simply this:

None of us knows when we'll go, or how long we'll have to endure the things we're called on to endure. That's Why it's so important to live every day the best you can. Some days will have more rain than sun, more wind than calm. Rising above the storms of life is the still small voice of gratitude. It beckons us to look beyond our present pain. It invites us to take one step, then another, to look for the good, to lift the hand that hangs down. Indeed, life's most challenging trials can be divine lessons in gratitude. So much of life, its beauty and gifts, can nourish our souls. To give and to be given to, to love and to be loved, to care and to be cared for, to help and to be helped, to lighten each other's burdens and show each other the way to a more abundant life... these are the things that enrich our lives and the lives of others.

Anyone can learn to be happy, to love and care for others, to go forward with strength and courage. We do it the same way we learn to type, play the piano, play ball or become proficient at any skill... through practice, constant practice. So, practice taking the time now to laugh, to love, and to help someone along the way. That's all that God expects of us. If we lived each day as if it were our last, I think we'd try to live it the best way we knew how. One day, all of us will have to step across that threshold into another world, a better world, where every person who's ever lived on this earth either *has* gone, or *will* go. We will know then, that ***this thing we call death is really just another birth.*** Only this time, we'll enter into a

world where suffering and misery will be simply be distant memories of our journey here on earth.

I want everyone to know how much I've gained by going through the trials that I've gone through in my life. I'm so grateful for the strength I've gained and for the lessons I've learned.

I don't believe in words like "can't," or "won't." I refuse to feel sorry for myself. None of that! It's always "I think I can," or "I know I can," "You must do the things you think you cannot do!"

I believe I was supposed to Write this book so I could help people understand, that even though we all have trials in life, life is still worth living. And as strange as it may sound, it's often those very trials that we have to endure that ultimately give us depth, understanding, and a true appreciation for the good things in life.

It's my hope that if someone is struggling with health, or rejection, worry or stress... whatever it may be, that they can find a story from the pages of my life which will resonate with them, and help them better cope with the problems they have. I want people to know that even though they have bad things happen in their lives, they can survive, and emerge wiser and stronger than they were before. I want people to believe they can survive, and find the will and the desire to live, one day at a time. We all need to know that bad things happen to good people, and our trials and pains are in no way a condemnation or punishment from God.

I hope that anyone touched by this story will understand that they can be happy, even in the midst of their sufferings, and that they can smile through all the pain. I know, because I've done it. It makes such a difference in your life to get up in the morning and go outside and smell the roses. We need to take time to see the beauty of the world around us, to sit in the sunshine, and feel the joy of simply being alive.

I also believe that this book will help Jeremy. Through our speaking and singing engagements, I've noticed that he has a special ability to connect with people and help them put the everyday problems of life in proper perspective. As he helps others to understand what they should be grateful for, it helps him understand that there's a purpose and a reason for all the things that he's gone through and continues to go through. He loves to sing. He has a soft spot in his heart for music. He loves to make people laugh and be happy. When he does that it makes him feel like he's being of service to someone in a truly important way.

I really appreciate all the people who have done so much for us over the years. For all their kindness and generosity, and now I want to return some of that kindness to them. I'm so grateful for wonderful employers who have stood by my side, and accepted me, even with my disabilities, and given me a chance to do all the things I've been able to do. I'm grateful for all the kind people who've donated money to help us out, and the people who have remembered us in their prayers.

I'm grateful for all those who have been there for us. I need to say how much I love both sides of my family. I love my mom and dad as well as Lee's parents, who have been so good to us over the years. I will always be grateful to them. I hope that by reading this book, all our friends and family will know just how much we love them, and how grateful we are to them for their support. Without the love of family, friends, and God, life would not be worth living.

I want you to know that our trip to Johns Hopkins was very good for Jeremy and me. It was good for Lee as well, and it was good for the rest of our family, even those who didn't come along. I think it's helped us just by giving us the knowledge we now have. To really know what it is you're dealing with is very helpful. Knowledge is amazing. Watch Jeremy. He's become more excited about the future.

We were told of one lady who had this disease and lived to be seventy-six years old. When I heard that, I said, "Well, I guess I'll just have to break her record!" Then Jeremy said, "Yeah, and I'm going to break Mom's record." I hope he does.